

**ORGAN DONATION AND TRANSPLANTATION: THE
PARADOX OF GIFTING AND DIS/EMBODIMENT**

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This PhD thesis is dedicated to the memory of my father, Thomas Haddow.

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Abstract

Since the 1950's, procuring organs for cadaveric transplantation has been based around a "gift of life" discourse, institutionalised through the carrying of donor cards/driving licence or registration on the NHS Organ Donor Register. Yet regardless of whether, or how, the deceased recorded their wishes to donate, their next-of-kin are always asked if organs can be removed. Little is known about the reasons families give for refusing or agreeing to an organ donation request. In order to identify the circumstances, in which an organ donation request is more likely to be accepted or refused by the family of a brain stem dead individual, eighteen semi-structured interviews were carried out in various areas of Scotland, in order to ascertain donor and non-donor relatives' beliefs, attitudes and experiences. The findings suggest that wider cultural beliefs embedded in society about the value of gifting, death and the body are brought to the specific context of an organ donation request. The interactions between these values and other factors, such as familial and hospital support and dynamics, and the perceived value of the outcome from donation, which affect whether families will donate or not. The findings of such an investigation will have obvious policy implications for those interested in increasing the present UK organ procurement rate, and can also inform debates about the merits of introducing alternative systems. However, a study of organ donation and transplantation can also provide the sociologist with a unique insight into several engaging areas of sociological interest: modern gift practices (including altruism and social exchange theory), the way meanings are constructed onto dead bodies by different groups, how and when death is defined, and finally, how individuals view the relationship between personal, social and corporeal identity.

Organ transplantation is a relatively new medical therapy, approximately only fifty years old. Yet over this limited time span it has proved to be an exciting and controversial procedure. Not least for its experimental beginnings and life saving and enhancing properties. Though the technology to conduct such intricate surgical procedures may be with us, organ transplantation depends crucially on individuals' ability and willingness to donate their organs on the occasion of their death.

Since the 1950's, in the UK procuring cadaveric organs has been promoted on a "gift of life" discourse, institutionalised through the carrying of donor cards/driving licence or registration on the NHS Organ Donor Register. Yet regardless of whether or how the deceased recorded their wishes to donate, their next-of-kin are always asked whether organs can be removed. If the wishes of the deceased are known, almost 95% will agree to donation (King's Fund Institute 1994) however, studies have shown in the absence of such knowledge nearly 30% of relatives will refuse (Gore *et al.* 1991, BACCN/UKTCA 1995). This refusal rate is a contributory factor to the current shortage of organs; the absence of a donor card may be interpreted by the relatives as an indication the deceased did not want to donate. Yet little is known about the reasons families give for refusal (though see BACCN/UKTCA 1995) or for that matter agreement (Fulton *et al.* 1987, Sque and Payne 1996, 1998). At present, there is a lack of qualitative research which offers a comparative approach into the beliefs, experiences and attitudes of both donor and non-donor relative families. My own research addresses this deficiency, by identifying the circumstances in which an organ donation request is more likely to be accepted or refused by the family of a brain stem dead individual. So, the unique contributions of this thesis are, firstly, it examines the relationship between several, distinct, but arguably inter-related areas. In the broader background are general socio-cultural beliefs about gifting, death and the dead body. On a meso- and micro-level are family dynamics and health professional support and information, and beliefs about the value of organ donation. My aim is to establish in what way such areas can contradict or reaffirm each other. This sociological study, therefore, offers an original, conceptual model that highlights the inter-connected nature of socio-cultural values previously only considered in isolation from one another. Such an argument, therefore, takes account of wider cultural and social beliefs, but also contextualises them within a medical environment on the occasion of a next-of-kin's death, surrounded by family and friends, and with specific beliefs about organ donation being taken into account. Secondly, such findings have obvious and important policy implications, and can enable current policies to be assessed. This research can inform strategies to maximise the present rate of organ

procurement and contribute to debates regarding the merits of introducing alternative, European organ procurement systems.

Organ Donation and Transplantation: Past, Present and Future

In order to provide context and background, Chapter 2 will offer an overview of the historical developments of organ transplantation, locating some of the major landmarks and breakthroughs establishing it as a medical therapy, and looking ahead to new developments. Fascinating as these developments might be, organ transplantation depends on the most singular of resources – organs. One of the acute problems currently, is that body parts supplied are not meeting demand, a trend likely to continue in the foreseeable future. There are two solutions to increasing the available number of organs: a change in *system* and/or a search for alternative *sources*. A possible immediate change in the UK organ procurement system will be reviewed, alongside an assessment of European and American procurement systems. Crucially, such changes involve legal, social, religious and cultural attitudes towards death, the body and its parts and, therefore, will be mediated by public opinion. Moreover, changes in procurement do not address the fact that the availability of cadaveric organs is steadily decreasing. There are various factors that influence the availability of cadaveric organs, including the number of road traffic accidents, population density, improvements in medical technology etc. All of these are outwith organisational control. This leads to the second option that locates the potential for utilising other sources to alleviate the shortage: living donation and animal-to-human transplants. Each, however, has associated social, ethical and practical implications. I will suggest, moreover, research into the present practice of cadaveric organ donation is immediately beneficial and valuable, before attempts are made to introduce wholesale changes to systems or sources.

In order to determine what is already known about donor and non-donor families, an overview of previous research is next provided. In Chapter 3, the main conclusions of both quantitative and qualitative studies conducted in the UK and elsewhere are reviewed, providing a coherent overview of non-donor and donor family experiences, attitudes and beliefs. This chapter begins by re-examining demographic factors and groups together the main characteristics of donor and non-donor families. Demographics are useful in locating group differentials in the population, but do not explain why individuals within groups donate or not. Therefore, research examining the rationale for donation is significant and the findings of donor family studies will be outlined (Bartucci and Seller 1986, Fulton *et al.* 1987, Tymstra *et al.* 1992, Douglass and Daly 1995, Sque and Payne

1996, Dejong *et al.* 1998). In order to provide a comparative overview, attention then turns to the limited amount of research available about non-donor families, and reasons offered by researchers why they reached their respective decision (BACCN/UKTCA 1995, Tymstra *et al.* 1992, Dejong *et al.* 1998).

Context and Actors within an Organ Donation Request: Familial and Health Professional Support

In Chapter 3, a review of previous research demonstrates the important influence of inter- and intra- familial dynamics (including the deceased's wishes on the matter) and interactions with health professionals. These two groups are identified as having potential influence over the decision to donate. Health professionals play a crucial role in organ donation, not least for their part in negotiating a donation and the provision of support and information to the family. They can, for example, offer the families an understanding of brain stem death or reassure them about the procedures involved in removing the organs. The way the family interacts with health professionals is likely to have significant repercussions. Studies have shown, however, that health professionals continue to be the "weak link" in organ procurement (Prottas and Batten 1988, Gaber *et al.* 1990, Pelletier 1993). For example, some health professionals are emotionally and conceptually confused about brain stem death and, therefore, they may have difficulty in effectively communicating understanding to grieving family members (Younger 1990).

The second significant group involved in the decision to donate organs or not is the family, and the impact of their beliefs and dynamics are also important. Questions raised in Chapter 3 include, whose influence counts in making the organ donation request? Who is approached with the request and which family members are consulted may also have significant repercussions. Research has suggested a request is more likely to be refused if there is familial tension about the decision (UKTCA/BACCN 1995). However, the source of this tension is not identified, and neither are possible factors that lead to its resolution. Thus, the belief systems and attitudes of significant others may have either positive or negative repercussions, and require further investigation.

Belief Systems about the Value of Organ Donation

So, the family's own beliefs about the perceived value of organ donation and transplantation are also likely to have some bearing on their decision. Studies outlined in Chapter 3 will show that more members of donor families than non-donors would be willing to accept a transplant, donor families were more likely to think people benefit

from transplants, and were also more likely to know the deceased was in favour of organ donation (Dejong *et al.* 1998: 15). Non-donor families were more likely to state it is important that a person have all their parts when buried, and were more likely to believe more could have been done to save the deceased's life. They were also more likely to know donation was against the wishes of the deceased (Dejong *et al.* 1998: 15). These findings are confirmed by other research, which show individuals who thought transplantation was a proven procedure, or who knew someone who had received an organ, were also more likely to donate (Burroughs *et al.* 1998: 156). Therefore, a positive belief system about the value of organ transplantation is a significant factor in the decisions to donate or not.

Gifting

The limitations and contributions of studies in Chapter 3 inform both the theoretical and empirical focus in the rest of the thesis. The theoretical focus is structured around two main themes – *gifting*, what families do by donating organs and the *body*, what families may or may not donate. Taking gifting first, in Chapter 4, I outline the arguments of some researchers that donor families donate because they are altruistic (Fulton *et al.* 1987, Batten 1990). Statements about altruistic values are employed by the medical profession and the media alike to encourage individuals to donate their organs. However, it is not clear what is meant by the term “altruism.” Is donation termed altruistic because individuals take part in a voluntary, other-motivated, anonymous system and cannot expect any reward? Related issues include the difficulty in discerning individual motives, the role of the donor card and the problem of separating the family's altruism from their desire to carry out the wishes of the deceased.

Drawing upon the work of the anthropologist Mauss (1954), whose theory of gift exchange has been applied to blood donation (Titmuss 1970) and, more recently organ donation, researchers argue organ donation is an example of social exchange theory (Fox and Swazey 1987, Sque and Payne 1992). The decision to donate is obligatory, self-interested and reciprocal as opposed to the voluntary, other-motivated and unreciprocable premises donation is supposed to stem from. In Chapter 3, a detailed theoretical exposition will be given to the concept of “altruism.” The applicability of Mauss's work to organ donation is questioned here, and other complementary explanations sought. The chapter includes a discussion of the norms of reciprocity and beneficence (Gouldner 1973), a deliberation on the existence of altruism, and an examination of the “moral economy” (Thompson 1971), an area of life where non-market transactions occur. In

order to test whether the principles of social exchange or altruism are at work in the decision to donate organs, three different rationales are explored – whether the donation is obligated or voluntary, whether it was self-interested or other-motivated, and finally if there was an expectation of reward.

Death, The Body and its Parts

Gifting will, therefore, receive closer theoretical scrutiny, in order to establish why donor families donate. Of equal importance is why some families refuse, and I suggest those beliefs about the gift (the body) and the conditions it is given under (death of the individual) pose obstacles to donation. In Chapter 5, discussion turns to how relatives construct meanings around death, the dead body and its parts. That is, for donation to occur depends on relatives' accepting both the death of their next-of-kin and, surgical procedures to the dead body. The limited amount of available evidence suggests mutilation of the body is a concern both donor and non-donor families face (Fulton *et al.* 1987, Tymstra *et al.* 1992, Douglass and Daly 1995, BACCN/UKTCA 1995, Sque and Payne 1996, Dejong *et al.* 1998).

Death is, of course, intrinsically linked to organ transplantation, dependent as it is on the demise of the individual. In order for donation to occur, an individual must be diagnosed as brain stem dead (BSD). In contrast to traditional cardio-pulmonary means, where cessation of heart beat signals death has taken place, with BSD respiration continues, albeit through the artificial means of the ventilator. Relatives are dependent on communication from health professionals regarding this diagnosis and their role may be pivotal in the negotiation of an organ donation request. In short, if relatives do not accept death has taken place they will be more likely to object to an organ donation request.

Equally, the dead body is not a value neutral biological entity and, I will argue, continues to represent the identity of the person it was once co-existent with. Further complications arise if the family believes the newly dead body continues to represent the person – anxiety may be caused about whether procedures will violate the body's integrity and identity. In other words, because the next-of-kin will continue to have bonds with the deceased what happens to the body will remain a matter of concern. Simply put, in a secular, material world, *bodies die, relationships don't*. In support of such a claim, evidence suggests biological and social death need not occur at the same time, and a person can become detached, or dis-embodied, before death (Glaser and Strauss 1965, Sudnow 1967). If a person can die socially prior to biological death, then the converse

may also be true - the person can continue to be socially present after death (Klass *et al.* 1996, Mulkay and Ernst 1991, Walter 1996b). In other words, I ask do dead people die? In what ways does physical dis-embodiment result in an expansion of social presence? If this is the case, in what ways does this phenomenon interact with the donation of organs? What are the implications post-donation, when parts of the deceased physically persist in recipients? Do donor families desire contact with the recipients? And how much information should be provided to the donor families about them?

This chapter of the thesis entails pulling apart taken-for-granted assumptions about the relationship between a person and their body. As living individuals, our interactions depend on having bodies to interact with. To give presence of self is dependent on being embodied. Using a body, a person's body, for procedures like organ transplantation raises fundamental questions about our personal and social identity. Organ transplantation depends on a view of the body as not equated with the person, a perception of the body as merely a machine from which a series of interchangeable parts are removed. This view, known as Cartesian Dualism, is one promoted by the medical professional. But the relatives may not share this view and have a more embodied, holistic version of the body. For simplicity, relatives and health professionals are treated as homogenous entities, whilst realising that this is an over generalisation and ignores diversity within. One should also be wary of drawing such tight dichotomies positing Cartesian objectivity and holistic subjectivity on opposing sides. Such differences may, however, be characteristic of these groups, though the origins of such beliefs are unclear, their pervasiveness unknown and the demarcation of boundaries ambiguous.

Because it was recognised the research was sensitive in nature, and required access to NHS resources and staff, ethical approval was sought and approved by three NHS Research Ethics Committees throughout the course of the study. In Chapter 6, a description is offered of the processes involved in negotiating ethical approval, and how the main concerns of confidentiality, anonymity and the avoidance of unnecessary distress to the respondent were resolved. This chapter also outlines the recruitment process and response and agreement rates. Additionally, a comment is made on the development of the interview schedule, demonstrating why certain areas of study were chosen, and in what way questions are linked to the generated theoretical concepts.

Due to the parameters of similar research carried out in the United States (Fulton *et al.* 1987) and the limitation of time and resources, a retrospective study of 15 donor and non-

donor family respondents was initially planned. The willingness of respondents to participate and the logistical problems of tracing them, however, affected the final sample. In total, 15 interviews were conducted with donor families, and due to the invitation to bring another family member, 19 donor next-of-kin involved in the donation request were finally interviewed. For reasons to be outlined later, only three interviews (four respondents) with non-donor next-of-kin were carried out. The study focuses principally on the experiences of donor families, though some speculative points of comparison are drawn from the smaller sample of non-donor families in Chapter 8.

I tested the aforementioned theoretical concepts and hypothesis during the course of the fieldwork and all interviews were transcribed, coded and then analysed using NUD*IST QSR 4. The findings of interviews with donor family respondents are offered in Chapter 7, and are thematically presented commencing with how the respondents socially constructed death, the dead body and its parts and whether this posed any obstacles to donation. In turn, the impact of hospital and family dynamics are offered, before a discussion of their beliefs about organ donation specifically, and gifting in general. Finally, thoughts about the recipients and the impact of bereavement are outlined. As mentioned, in Chapter 8, a short discussion of non-donor families will be offered, highlighting similarity and divergence to the findings of donor families. Though the sample size limits what can be confidently concluded from their accounts, a comparative approach with donor families demonstrates the way in which non-donor and donor family beliefs, attitudes and experiences differ, and identifies the factors for why donation did not occur. It is argued in this thesis, that the gifting of organs can be considered in light of the “sacredness” of moral phenomena, of “sympathy for all that is human, a wider pity for all sufferings, for all human miseries, a more ardent desire to combat and alleviate them” (Durkheim quoted in Giddens 1972: 23). Yet in doing so, the socio-cultural significance of the sacredness attached to the body may have to be transgressed. Therein, I will argue, lies the paradox of organ donation and transplantation.

Introduction

In the Wurtembergisches Landse museum in Stuttgart, hangs a fifteenth century painting depicting the patron saints of physicians, Saints Damian and Cosmos, transplanting a leg from a donor to a Nun, with God and a chorus of angels surveying the scene (Barkan 1996). This painting is obviously not an accurate representation of medical therapies at that time, but a religious portrayal of a “medical miracle,” a theme continuing into the twentieth century, when transplanting organs can offer the potential of significantly improving and prolonging life (O’Neill 2001: 1). Organ transplantation is, therefore, not a new concept; yet the reality of removing an organ from one individual to transplant into another is only approximately fifty years old.

As a procedure, organ transplantation depends on perhaps the most singular of resources – organs donated by individuals on the occasion of their death. At present the UK donation rate is not meeting demand and with continuing improvements in organ transplantation, and an ability to transplant an ever-increasing range of organs, the gap between supply and demand is likely to increase. The first potential option to alleviate this situation is an immediate short-term change in the way organs are procured. In the UK, organ procurement is based on a voluntary opting-in system, based and promoted by the medical profession and the media, on the social values of voluntariness and altruism. Individuals, on this basis, carry a donor card or register on their driving licences/National Organ Donor Register, choosing to “opt-in” to organ donation after their death. However, their family’s *lack of objection* is always ascertained.¹

Nevertheless, because of the perceived failure of the voluntary UK donor system, calls have been made by organisations such as the British Medical Association to change the system of procurement, with alternatives such as required request or presumed consent. It will be suggested in this chapter that, though introducing other systems may be immediately beneficial, such a change side-steps the important issue of a general decrease in cadaveric organs. The rate of cadaveric donation will continue to be affected by numerous and complex factors outwith organisational control, for example, the rate of

¹ This is the wording used in the UK 1961 Tissue Act. However, in the wake of the publicity surrounding the “retention of organs” episode, to be discussed later in this chapter, the Department of Health report (Donaldson 2001: 27) has criticised this terminology, as “outmoded and paternalistic.”

road accidents resulting in brain stem dead individuals and a country's population density.

The second option is to examine alternative sources. In other words, long-term changes must examine other means: potentially either living or animal transplants. Turning to a discussion of living donation, when an individual donates one of their paired organs to a related other, raises different issues from cadaveric donation. Living donation is not widely practised in this country for several reasons, primarily, as it violates the Hippocratic oath of "first do no harm," and contradicts the principles of anonymity and voluntariness cadaveric donation rests on. It is well documented in living donation, that some family members offer to donate as soon as they hear of a relative's need for an organ (Simmons *et al.* 1987). To a degree this may subvert the issue of "informed consent." Because living donation mostly occurs in the social context of familial relations, donation is likely to be affected by emotional bonds that, in general, are found amongst next-of-kin, therefore implying a more "obligated donation."

Alternatively, rather than looking at human sources, some scientists have recently suggested animals may offer a viable option. Xeno-transplantation has occurred since experiments in organ transplantation began, with xenografts attempted at the beginning of the twentieth century. Recent developments in cloning, potentially allow the vexing problem of rejection of the organ by the recipient's defence system, to be overcome. Yet it may be ethically questionable to create animals purely for transplantation. The practical implications for the recipient are unknown, as are the risks involved with the transmission of disease cross-species. Further, to what extent are individuals likely to be comfortable accepting such procedures?

To commence, an overview of landmarks in the history of organ transplantation will be offered, outlining past innovations and examining potential future developments. Initially, the focus will be on cadaveric donation examining the increasing demand for transplants, followed by an appraisal of factors that influence the limited number of organs available. A more immediate alteration in the donor rate could potentially lie in changing the procurement system, and European and American alternatives will be examined in more detail, and their applicability to the UK situation assessed. In turn, the discussion will review legal, social and religious attitudes towards cadaveric organ donation. In contrast to cadaveric donation, the limited amount of information regarding living donors will be offered, followed by a short summary of xenotransplantation. The

sociological implications of cadaveric, living and xenotransplantation will be drawn out and discussed at greater length towards the end of the chapter. Throughout this overview it will become apparent that differing social contexts of organ donation have different implications, both at the micro and macro level, for donation rates and acceptance of procurement systems and sources.

HISTORY OF ORGAN TRANSPLANTATION

It is claimed the first attempt at blood transfusion took place five hundred years ago in 1492, when a dying Pope Innocent III received blood from three healthy, young boys. The Pope and the boys died, and soon after the physician fled (Kimbrell 1993: 7). Others suggest the first transfusions occurred later in the seventeenth century, certainly stimulated by the work of William Harvey, who had made a significant breakthrough in the understanding of blood and circulation, comparing the heart to a mechanical “water pump” (Marshall and Bird 1983). In 1665, the anatomist Richard Lower united the artery of a dog to the vein of another with a hollow quill. Two years later in London, Lower took another step forward when he transfused the blood of a lamb into a “healthy, but mildly insane man ... who got twenty shillings for his trouble” (Kimbrell 1993: 8). Surprisingly the man survived, given that in 1818, James Blundell showed animal blood was not compatible with human blood, thereby accounting for the numerous failures of previous attempts. It is Blundell who is eventually credited with the first human-to-human blood transfusion (Kimbrell 1993: 10).

Skin Transplants

At the beginning of the nineteenth century attempts at skin transplants were carried out on animals, nevertheless, it was not until the end of that century human-to-human skin grafts were performed. One of the most vivid examples of this, is an account given by Winston Churchill of the Sudanese war in 1898:

Molyneux had been rescued from certain slaughter by the heroism of one of his troopers ... While we were talking, the doctor came to dress his wound. It was a horrible gash, and the doctor was anxious that it be skinned over as soon as possible. He said something in a low tone to the nurse, who bared her arm. They retired to a corner, where he began to cut a piece of skin off her to transfer to Molyneux's wound. The poor nurse blanched, and the doctor turned on me ... there was no escape, and as I rolled up my arm ... he then proceeded to cut a piece of skin and some flesh about the size of a shilling from the inside of my forearm ...

This precious fragment was then grafted onto my friend's wound. It remains there to this day (Rapaport and Dausset 1968 quoted in Kimbrell 1993).

Winston Churchill can be considered as one of the earliest examples of a tissue donor. His apparently beneficent act set a precedent, and today all organs and tissues are procured through "voluntary donation" based on the principles of altruism and gifting, with the "gift of life" becoming the cornerstone of the British cadaveric organ and tissue procurement system.

Corneal Transplants

In 1905, one of the earliest reported cornea transplants was carried out in the Moravian town of Olmutz (UKTSSA Annual Report September 1994). This is now an extremely successful procedure with over 90% of cornea transplants still functioning after one year. In Britain, the Cornea Transplant Service, established in 1983, enabled corneas that could not be used locally to be made available to other surgeons for transplantation. This facility was enhanced three years later with the Bristol Eye Bank, and in 1989, the Manchester Eye Bank (UKTSSA, Annual Report, September 1994). Because corneas can be stored for up to thirty days in an Eye Bank there is rarely a shortage for emergency grafts and transplants can be planned well in advance. At any one time, roughly three hundred transplants are available, and the CTS Eye Banks supply to over two hundred hospitals for over two thousand eye transplants a year (UKTSSA Annual Report, September 1994).

The Role of Immuno-suppressants in Transplantation

The first scientific breakthrough regarding the transplantation of solid human organs did not occur until the twentieth century. In the 1940s, Sir Peter Medawar demonstrated the body's immune system rejects foreign materials, and thus tentative steps were made into the development of tissue typing (Kimbrell 1993: 26). Tissue typing helped in overcoming one of the greatest obstacles to organ transplantation, namely "rejection." Rejection is a result of the body's defence mechanism, the immune system, attacking any foreign body. Every cell in the body has a marker called "antigens" on its surface. These antigens are determined by genes (human leukocyte antigen, HLA) passed on through parent to child. With a better definition of the antigens, enabling the immune system to distinguish between "self" and "non self" comes a significant improvement in the success of transplantation, as it is possible to match recipients and donors with the same HLA type and, therefore, limit the process of rejection.

Continuing medical improvements of immuno-suppressant drugs, such as cyclosporin-A (and more recently prednisone) aided the routinisation of transplantation during the eighties. These drugs help modify the recipient's immune system, preventing the graft being rejected.² Together with the development of the ventilator, and other advances in areas such as tissue preservation that allowed the sharing of organs between transplant centres (and thus the best HLA match could be located for waiting recipients) transplantation metamorphosed from an experimental procedure to a successfully established therapy.

Organisation of Allocation and Procurement

Alongside such technological developments came progress in the organisational aspects of donation. As is apparent from the discussion of corneal transplantation, the procurement and allocation of organs is a highly complex process, with communication and co-ordination occurring between hospitals, geographically dispersed throughout the country. Thus, population density has an important part in a country's organ donation rate. In less densely populated countries, an individual suffering from a cerebral trauma, has a longer distance to travel to hospital, making "it harder to reach and transport patients to ICU, [intensive care unit] and more difficult and time consuming to collect and transport organs without affecting their suitability" (King's Fund Institute 1994: 28). This geographical disparity is compounded with a limited time span in which organs can be preserved. Organs only have a limited "ischemic" time (lack of oxygen to the organ) after removal and integration into a recipient. The following (Table 1) is the maximum length of time organs can be preserved outside the body.

Table 1 – Preservation Time of Organs

Organ	Preservation Time
Heart/Lung	4 - 5 hours
Heart	6 - 8 hours
Lung	Up to 12 hours
Liver	12 - 24 hours
Kidney	48 - 72 hours

² Immuno-suppressive drugs have to be taken for the rest of the recipient's life, and do have serious side-effects, and it is not altogether guaranteed that these drugs can prevent a case of chronic rejection.

Working within such an extremely short time frame means that, unlike other medical procedures, organ transplantation depends on a tightly co-ordinated system (Machado 1998: 7). In Britain, once a potential donor has been identified the intensive care unit (ICU) staff notifies the transplant co-ordinator. The co-ordinator then contacts the United Kingdom Support Service Authority, an organisation that holds the UK wide database of all patients awaiting transplant. Once an HLA match has been made between donor and recipient, the donor's hospital permits a transplant team to surgically remove the organs. If a donor is providing multiple organs, various surgical teams arrive at the donor hospital to remove the required organs with generally, the heart, lungs, and liver being the first organs to be removed, due to their short ischemic time. Machado (1998) offers a comprehensive, sociological account of an organ transplantation system, demonstrating how such a large-scale and highly complex organisation is an example of "*interdependent technical heterogeneity*" (1998: 7, original emphasis). That is:

... such systems link a wide spectrum of varied technologies and occupational and professional groups - not only medical but non-medical ... because organ transplantation systems are, both spatially and functionally, widely dispersed, they require a high degree of standardisation and *compatibilisation* of the organisation, the communication systems, and exchange systems ... They are science-intensive but also highly dependent on public acceptance and legitimisation (Machado 1998: 7).

In less industrialised countries such as India, organs are largely procured through living donors, in part because the country does not have the necessary funding, organisational skills and technical infra-structure, accompanied with appropriate legalisation to organise the procedures for cadaveric donation.

Cost of Transplants

Contrary to popular misconception, transplantation is a relatively inexpensive procedure (Nuffield Council of Bioethics 1996: 2). A kidney transplant costs approximately £10 000, with follow-up treatment of about £3 000 per annum. Dialysis, on the other hand, can cost up to £18 000 per annum if treated in the hospital, and £11 000 if the patient is treated at home. Therefore, a kidney transplant is more cost-effective than maintaining a patient on dialysis. Other costs are dependent on the time that the patient stays in hospital. Heart transplants can vary from £10 000 to £18 000 and liver transplants can

cost from £15 000 to £18 000 with follow-up treatment averaging between £3 000 to £5 000 per annum (Nuffield Council of Bioethics 1996: 2).

Kidney Transplantation

Early experiments in tissue transplantation are useful examples highlighting the fraught nature of this type of work which was mirrored in later experiments of solid organs.³ Locating historical landmarks in the development of organ transplantation as a procedure is difficult. The existence of conflicting records about what organ transplant was performed first, by whom and where, are in large part due to the failure to keep accurate records in the early beginnings of transplantation. It appears the first successful attempts at transplantation only occurred in 1946, when a cadaveric kidney was attached to the arm of a woman suffering from septicaemia and anuria (Brent and Sells 1989: 35). After three days the kidney was rejected, but by then the patient's own kidneys were functioning. Shortly after this, renal dialysis became more widely available, and there was no longer the need for such short-term transplants. In 1951, Dr David Hume together with Dr Joseph Murray attempted over the next four-year period, to transplant ten kidneys, all of which failed (Kimbrell 1993: 26). The first successful fully functioning kidney transplant operation was performed in 1954, when Dr Murray and his team carried out a kidney transplant between two American identical twins (UKTSSA Annual Report 1996). By 1975, kidney transplantation had become a routine procedure, with over twenty five thousand transplants carried out worldwide per annum (Scott 1981). In 1999, the UKTSSA annual report suggested that after one year post-transplant, 85% of recipients still had a functioning graft, and a kidney transplant is now the "treatment of choice" for those patients with end-stage renal failure. Kidney transplantation not only increases longevity, but also the patient's quality of life. Recipients do not have to spend long, uncomfortable and frequent periods on a dialysis machine. They are also able to travel, and eat and drink freely in a way that long-term dialysis patients cannot (Nuffield Council on Bioethics 1996: 2). In unsuccessful cases, when the kidney is removed or rejected, dialysis can be resumed until a new donor is available. Kidneys are, at the moment, one of the most successful organs to be transplanted due to their relatively long recipient survival time.

³ It could be argued these pioneering tissue experiments do not strictly constitute what is meant by organ transplantation. Blood, skin and corneas, arguably do not require the same surgical expertise and medical technology as transplanting solid organs, yet they are historical illustrations of living donation and animal-to-human transplants (xenotransplantation) considered preludes to cadaveric transplantation.

Heart and Lung Transplants

On the other hand, lung transplants are arguably the least successful transplant procedures, due to their low recipient survival rates. In 1963, Dr Hardy performed the first lung transplant in controversial circumstances. The recipient, Mr John R. Russell, was serving a life sentence for murder, and his death eighteen days later raised allegations he was no more than a “guinea pig” chosen for a lung transplant as he had had nothing to lose (Rosenberg quoted in Kimbrell 1993). In December 1983, a British team at Harefield hospital performed the first combined heart and lung transplant (UKTSSA September 1994). This procedure was developed for patients who had primary lung disease, or congenital heart disease with secondary lung disease. In April 1987, the Harefield team also performed the first “domino” heart transplant (UKTSSA September 1994). For patients with lung disease, a combined transplant is the best therapy, and the healthy hearts from the recipients can be transplanted into patients requiring only a heart transplant. Lung transplants are the least successful organ transplants, with roughly 70% of patients who had a lung or heart/lung transplant surviving longer than a year (UKTSSA 1999: 29).

Heart Transplants

The first heart transplant invoked the highest amount of media coverage and public attention. In 1967, Dr Barnard transplanted the heart from a female car-crash victim, into the fifty five-year-old grocer, Louis Washansky (Brent and Sells 1989: 282). Washansky was to die eighteen days later of complications resulting from rejection (Kimbrell 1993: 27). The next year Sir Donald Ross performed the first UK heart transplant and imitations soon followed. The following year nearly 107 heart transplants, by sixty-four teams, in twenty-two countries were carried out, some with tragic results. Nowadays, with the advancements in medical surgery and immuno suppressive drugs, roughly 80% of British patients who receive a heart transplant, survive after one year (UKTSSA 1999: 29).

Artificial Heart

A fully mechanical heart, the Jarvik 7, was transplanted in 1969, into Mr. Haskell Karp by Dr Denton Cooley at the Baylor College of Medicine, Texas (Fox and Swazey 1978). The mechanical cardiac replacement remained for sixty-four hours before the patient died. In part, due to the controversy that ensued, this procedure was not attempted again until the early 1990's when developments with heart pacemakers occurred as a result of

sophisticated microchip technology (Gareth, *The Guardian*, Wednesday 2 1998: 2).⁴ Recently, American surgeons based in Louisville implanted an artificial heart into a terminally ill patient as a temporary measure to enable an organ donor to be located. At this stage, artificial hearts are still viewed as a “bridge” device (Gillan, *The Guardian*, Thursday 4 July 200: 2).

Liver Transplants

Conflicting historical records lead to a confused picture of the development of liver transplantation. For example, the first liver transplant, according to Miller (1971), was performed on a three-year-old boy at the University of Colorado Medical Centre, Denver on March 1, 1963. The boy died on the operating table. Kimbrell (1993) and UKTSSA (September 1994) however, both state the first liver transplant was carried out at Veteran’s Administration Hospital in Denver, by Drs T E Starzl and William Waddell, on a forty-seven-year old janitor, William Grimsby, who died three weeks later. Liver transplantation has expanded in recent years, and like kidney transplantation, is now a well-established procedure, with a survival rate of patients suffering from liver failure of 81% after one year (UKTSSA 1999: 35). Table 2 below, summarises the survival rate of all the major transplantable organs discussed above.

Table 2 - First Cadaveric Graft Transplantation Survival (UK and Republic of Ireland)

Organ	% survival at 1 year	% survival at 5 year
Heart/Lung	68	30
Lung	68	47
Heart	81	65
Liver	81	68
Kidney	85	83

Source: United Kingdom Transplant Support Services Authority, Transplant Activity, (1999).

⁴ Fox and Swazey (1978: 166) suggest Cooley was prepared to use the prosthesis despite inadequate clinical trials. This case also raises questions about informed consent. Mrs Karp, who was to file a medical malpractice suit against Cooley, claimed that her husband never knew that the mechanical heart had not been tested on a human being before and argued that “Haskell Karp was the unfortunate victim of human experimentation” (1978: 190). This was a charge that was not to leave organ transplantation in its formative years (see Fox and Swazey 1978 for a fuller discussion).

Transplantable Organs

Whereas historical records are conflicting regarding the development of organ transplantation, consensus exists around the modern-day technical ability of transplantation. Briefly, the full range of transplantable organs from cadaveric donors are: parts of the inner ear, glands such as the pancreas, pituitary, thyroid, adrenal and parathyroid, blood vessels, tendons, cartilage, muscles, testicles, ovaries, fallopian tubes, nerves, skin, blood, fat, bone marrow, cornea, liver, lungs, heart, pancreas, kidneys and the larynx (Scott 1981). Kimbrell's list of what one donor can potentially donate is worth quoting in full (1993: 28):

- 2 corneas to help restore sight
- 2 each of the inner ear, the hammer, anvil, stirrup, to ameliorate some forms of deafness
- 1 jawbone used in facial reconstruction
- 1 heart
- 1 heart pericardium (the sac that surrounds the heart is made of tough tissue that can be used to cover the brain after surgery)
- 4 separate heart valves
- 2 lungs
- 1 liver
- 2 kidneys
- 1 pancreas, which when transplanted can restore insulin production in diabetes
- 1 stomach (which has been transplanted experimentally without much success)
- 206 separate bones, including long bones of the arms and legs for use in limb reconstruction and the ribs used in spinal fusion and facial repair
- 2 hip joints
- About 27 ligaments and cartilage used in rebuilding ankles, knees, hips, elbows, and shoulder joints
- approximately 20 square feet of skin, which can be used as a temporary covering for burn injuries
- over 60 000 miles of blood vessels, mostly veins that can be transplanted to re-route blood around blockages
- nearly 90 ounces of bone marrow to treat leukaemia and a variety of other diseases.

The case of William Norwood, a twenty-two year old who died in a robbery in 1985, demonstrates that although transplantation has made significant medical advances, such progress can have tragic and unforeseen consequences. Norwood was HIV positive, a diagnosis that went undiscovered until at least four of the fifty-two different people who had received his organs, contracted and died of AIDS (Kimbrell 1993).

FUTURE TRANSPLANT DEVELOPMENTS

Other Transplantable Organs

In the United States, Dr Robert White has attempted whole body transplants with monkeys. One lived for two weeks with the ability to see, hear, smell, taste and breathe, but with no control over the new body (Evans, *The Guardian* Wednesday 2 1998: 2).⁵ Michael Wilks, chairman of the British Medical Ethics committee, argues on ethical grounds, even if such head transplants were feasible, it is likely that such procedures would be prohibited. Aside from the gamut of ethical, moral and social repercussions of such operations, ultimately transplants are for restoring “bodily functions not about preservation of the brain” (Evans, *The Guardian* Wednesday 2 May 1998: 2).

Face Transplants

More feasible and widely discussed developments are face and limb transplants. This recent initiative is moving transplantation from the interior of the body to the external surface. Among advances in plastic surgery is the ability to re-construct or re-attach faces to heads, a theme taken up by the film “Face-Off” (1998) where the protagonists “switch faces.” Apparently, within the next five years a face transplant could be performed for those patients suffering from burns or cancers (*Sunday Times Magazine* February 6 2000: 56). It would be unlikely, however, the recipient would actually look exactly like the donor. Our looks:

... are a combination of underlying bone structure and the overlying soft tissue. If you took just the soft tissue, then, for example, the lips would remain like the donor’s whereas some of the shapes, the squareness of the chin, for example, would be determined by the recipient. So the result would look neither completely like a donor nor like the recipient, but a blend of the two. If both the underlying

⁵For a more detailed examination of White’s earlier work which included transplanting brains in “neck pouches” onto dogs see Rapaport and Dausset (1968). The editors find it “fitting that a surgical approach to one of the most challenging problems of all times, transplantation of the brain itself, provides the last and possible vivid memory with which readers ... will be left (1968: 707). In contrast, this reader was perplexed that no mention of the potential moral and social repercussions of such transplants was made.

and surface structure were used, then that would increase the similarity to the donor (*Sunday Times Magazine* February 6 2000: 56).

Hand Transplants

In September 1998, a team of surgeons drawn from France, Britain, Australia and Italy succeeded in the first single hand transplant. The sixteen-hour operation involved having to connect all the tendons, muscles, veins and arteries from one wrist onto another, of recipient, Clint Hallam, whose own had been cut off in an accident (*Sunday Times Magazine* February 6 2000: 44). In January 2000, the same team of surgeons performed the world's first double hand transplant in Lyons, France (*Sunday Times Magazine* February 6 2000: 44). This was the first in a series of five transplants France will use to decide whether limb transplantation will become more routine (*Sunday Times Magazine* February 6 2000: 50).

STATISTICS ON SHORTAGE

There may be potentially new and exciting innovations but the more pressing issue pertains to the increasing discrepancy between demand for organs and those donated. Already, organ transplantation may have become a victim of its own success, with an ever-increasing gap between demand and supply. The following table demonstrates the number of patients awaiting a transplant at the end of 1999 in the UK.

Table 3 - Waiting lists for Organ Transplants in the UK (1999)

Patients in the UK waiting for:

Heart	289
Lung(s)	205
Heart/Lung	129
All cardiothoracic patients	623
All liver patients	180
Kidney	5835
Kidney and Pancreas	69
Pancreas	9
All renal patients	5913
TOTAL	6716

Source: UKTSSA Transplant Activity (1999: 6).

In the UK and Ireland at the end of 1999, 815 solid organ donors were identified (31 fewer than 1998 and representing a 2% decrease in the UK as a whole) providing 2708 organs for transplantation (UKTSSA, Transplant Activity 1999). Living donors provided an additional 310 solid organs (UKTSSA 1999: 4). The donation rate has remained static since 1990, levelling out at roughly 800-900 a year (Nuffield Council of Bioethics 1996: 16). Some have argued, if all cadaveric organs were used, that there would still not be enough to meet demand as only 1% of the population die from brain stem death (Caplan quoted in Nuffield Council on Bioethics 1996: 16, for a fuller discussion of brain stem death, refer to p. 37). Available statistics pertaining to the number of brain stem deaths from 1992-1994 show 3063 brain stem deaths were recorded (BACCN/UKTCA 1995: 5). As Table 3, shows there were 6716 patients awaiting transplants at the end of 1999, and 815 solid organ donors identified that year, providing over 2 708 organs. Arguably, if the number of donors were doubled, to approximately 1600 donors, then potentially there would be enough organs to meet demand, taking into account only 1% (3 063) of the population dies from brain stem death. This would depend on the present figures remaining at their current level. However, the cadaveric organ pool is decreasing.

Table 4 - Cause of Death of Donors 1999 (n = 815)

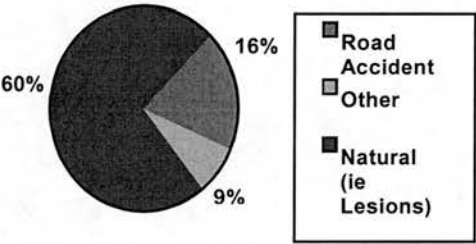


Table 4, gives a breakdown of cause of brain stem death in 1999, and demonstrates the greatest proportion of donors died from natural causes, such as brain haemorrhages and lesions. However, the size of the donor pool has been affected due to a decrease in the proportion of donors resulting from RTA (road traffic accidents). In 1988, RTA's accounted for 25% of all donors, but as Table 4 demonstrates, this fell to approximately 16% in 1999. In 1999, Britain's rate of road deaths was the lowest of any industrialised country, apart from Sweden and Iceland, and the lowest figure since records began in 1926 (Harper *The Guardian* September 10 1999: 2). This reduction is in part due to legislation regarding the compulsory use of front and rear seat belts and better road safety in this country. It may also account for the decrease in donors under 50 years of age (UKTSSA 1999: 9). In 1988, this age group accounted for nearly 30% of donors,

although in 1999 this figure had fallen to 25% (UKTSSA 1999: 9). The majority of donors however, still tend to be relatively young, as Table 5 demonstrates.

Table 5 - Donor Age

Donor Age	Number of Donors
< 18	97
18-50 years	431
> 50 years	287
Total	815

Source: UKTSSA (1999).

Steps in Organ recovery

Most of the organs procured for organ transplantation are taken from cadaveric donors, diagnosed as “brain stem dead.” In general, these are mainly young people who have died suddenly, usually through some form of irreversible damage to the brain. Brain stem death, as a phenomenon, arose in the 1950s, as a by-product of new resuscitation technology, though it was congruent with the early years of organ transplantation. During the fifties, it became clear to many physicians that some severely brain damaged patients, whose hearts and respiration continued, had little hope of regaining consciousness (Lamb 1990). Moreover, artificial ventilation could not be continued indefinitely - with certain brain functions missing the organs would eventually deteriorate. Brain stem death is not to be confused with persistent vegetative state (PVS). The former is analogous to being decapitated and unlike PVS, heartbeat and circulation will stop (Lamb 1990). There are heated medical and ethical debates regarding brain stem death, though it is sufficient for the purposes here to consider brain stem death as a reformulation of the traditional concept. Accordingly, loss of heartbeat and circulation may not be considered a state of death in itself, but an actual indication of its imminence.⁶ The main concern was the development of criteria that established there was no possibility the patient would regain consciousness, thereby sparing relatives further emotional stress. In 1968, the Ad Hoc Committee of the Harvard School to Examine the Definition of Brain Death published its report (which was to be adopted by most Western societies, including the UK). Three general conditions are to be satisfied prior to brain stem death testing: the patient has to

⁶ For an outline of the approaches and debates regarding the (re) definition of death see Gervais (1986).

be deeply comatose, maintained on a ventilator because respiration is inadequate, and the patient's condition is due to "irremediable structural brain damage" (The King's Fund Institute's Report 1994: 10). Having satisfied these conditions the following diagnostic tests can be undertaken:

- The pupils are fixed in diameter and do not respond to sharp changes in the intensity of light.
- There is no corneal reflex.
- The vestibulo-ocular reflexes are absent (a test involving the injection of ice-cold water into the ear and observing eye movement).
- No motor responses within the cranial nerve distribution can be elicited by adequate stimulation of any somatic area.
- There is no gag reflex or reflex response to bronchial stimulation by a suction catheter passed down the trachea.
- No respiratory movements occur when the patient is disconnected from the mechanical ventilator long enough to ensure that the arterial carbon dioxide tension rises above the threshold for the stimulation of respiration.

Source: (King's Fund Institute 1994: 10).

These tests must be carried out twice by two different physicians, one a consultant in charge of the patient, another a consultant or registrar independent of the first. Neither should be connected with the transplant team in any way in order to avoid a conflict of interest. The time between the tests is left to the physician's discretion, although a diagnosis of death should not be considered until at least six hours after the onset of a coma. Only if both physicians are satisfied the conditions have been met, is the person then declared dead (Working Party on Behalf of the Health Department 1983: 12). Once brain stem death is declared, and if the relatives' lack of objection is ascertained, the donor continues to remain on the ventilator, and medications given in order to keep the organs functioning. General surgical procedures are followed as it is essential that blood and oxygen are kept flowing to the organs until they are removed and preservation begins.

Organs can also be taken from donors not diagnosed as brain stem dead. Patients who have suffered from cardiac death close enough to a hospital so tubes can be inserted, and fluids can be flushed into the organs to cool them, can also become organ donors.

Patients who have asked for life support to be removed, and are expected to die shortly afterwards, can also become donors (DeVita *et al.* 1995: 26). Both groups of patients are known as “non-heart-beating” donors and taking organs from these sources is controversial (see DeVita *et al.* 1995 for further discussion).

Other Factors Affecting Cadaveric Donation Rate

Health professionals play a significant role in the identification of potential organ donors. In order to examine whether all potential donors were being identified, Gore, Hinds and Rutherford (1991) conducted one of the most comprehensive audits of Intensive Care Units in England. Of 497 possible donors, brain stem death tests were not carried out in 106 cases (26%) and cumulatively, only one hundred and forty one (50%) of 282 brain stem death patients became actual donors. Gore *et al.* (1991) concluded a number of potential donors were being missed and:

Four strategies [needed] to increase the supply of transplantable organs from brain stem dead potential donors in intensive care units were identified: (a) reducing refusal of relatives (b) avoiding non procurement of actually suitable organs (by logistical initiatives) and deterioration of initially suitable organs (by donor care initiatives); (c) converting restricted offers to unrestricted offers; and (d) ensuring discussion with the families (Gore *et al.* 1991: 149).

Others have counter-argued that, “this report indicated the potential for a small increase in donor numbers from patients within ICU’s, the scope for a major increase from this source did not appear to exist” (Fabre *et al.* 1995: 1). Moreover, contra-indications to donation may have been apparent to intensive care unit staff, who subsequently considered the carrying out of brain stem death tests pointless. As a result of modern imaging techniques, the predictive ability for patients with severe brain damage is much more sophisticated. The patient’s condition is diagnosed early as hopeless and subsequently, ventilation will not occur and the patient is not considered suitable for donation (Fabre *et al.* 1995: 1). Further, “inadequate resourcing of the transplant co-ordinator service and intensive care unit bed provision provides a barrier to an increase in organ donor rates” (1995: 1). The Nuffield Council on Bioethics reiterates this theme by arguing, “[T]he level of provision of intensive care units is lower in the UK than in other European countries and this is increasing evidence of a need to expand provision and staffing” (1996: 14).

RELIGIOUS, LEGAL AND SOCIAL ATTITUDES TOWARDS CADAVERIC ORGAN DONATION

The Legal Stance on Death and Donation

Since the definition of brain stem death, the British medical profession has long departed from the view that cardiac cessation is the end of the patient's life (Lamb 1991). However, one of the potential difficulties a transplant surgeon may face, is there is no statutory definition of death. The Criminal Law Revision Committee, in their fourteenth Report (quoted in King's Fund Institute 1994: 31) rejected a definition as, "it would amount to fixing an expression of present medical opinion in statute and could be outdated." Kennedy (quoted in King's Fund Institute Report [1973] 1994: 36 - 41) also suggests a legal definition of death could result in heightening public unease. Jennet (quoted in King's Fund Institute Report [1977] 1994: 36 - 41) disagrees, and claims such a legal definition is important so physicians do not face criminal charges. On the one hand, it would seem the Criminal Law Revision Committee's decision is unnecessarily cautious. It is likely that if any statute definition were enshrined in legal terms, it would be alterable. On the other hand, there is as far as can be ascertained, no incidence of surgeons having faced prosecution in the UK regarding the diagnosis of death suggest a legal definition may be unnecessary. It is interesting that lawyers are involved in the definition of death *per se*. Their involvement may be testament to the fact that the reformulation of death as brain stem death is still ambiguous, and not uncontroversial, in public opinion. The possibility that physicians would face criminal charges (which occurred in the United States, *People v. Eulo* see Zaner 1988: 113) highlights a continuing unease, between the widespread acceptance of the conventional definition of death, and the medical professionals' increasing reliance on brain stem death criteria.

Human Tissue Act 1961

The current legislation regarding cadaver donation is set out in the Human Tissue Act 1961. It states that if any person, either in writing or orally in the presence of two or more witnesses, has expressed a desire to donate their organs, then the person lawfully in possession of the body should honour such a request. The person who is lawfully in possession of the body may authorise the removal of any part of it for transplantation. What it does not state is who actually has, "lawful possession of the body." Furthermore, so long as whosoever is in lawful possession of the body has "no reason to believe" the deceased or any spouse or relative "objects," then organs may be removed for transplantation. However, "a single objection from any relative must be respected as it has the force of the Human Tissue Act behind it" (Farndale 1970: 2). What the

circumstances regarding this “reason to believe” are is vague and unclear; the suggestion “having made such reasonable enquiry as may be practicable” offers little guidance or direction. Farndale (1970: 9) suggests the Human Tissue Act must be read in conjunction with the Department of Health circular to hospitals, H. M. (61) 98, especially Paragraph 6:

Whether or not a request by the deceased has been made, authority for the removal of parts of bodies must be given separately in each case by the person lawfully in possession of the body. If the patient has died in hospital, this is the Hospital Management Committee or Board of Governors (until executors or relatives claim the body)...

Then, if the patient dies in hospital, it is clinical staff who have legal possession until the next-of-kin arrives. The interesting question of who has legal possession of the body is in part resolved, and the answer demonstrates that after death, in legal terms, the individual’s body belongs to the family. However, though it may be clear the relative is in legal possession of the body, the concept of “absence of refusal” for donation, and post-mortem, rather than the “giving of consent” had widespread political and social ramifications in the light of the Alder Hey incident. This episode was to demonstrate the archaic nature of a forty-year old law shown to be out of date with current sensibilities.

Alder Hey – the current climate

During 1999-2001, the media reported certain hospitals in the UK, such as Alder Hey and Bristol, had retained organs after post mortem without the permission of the parents.⁷ Relatives involved in the retention of organs incident complained they were not given enough information and guidance (and in some cases were not even aware organs had been taken). This incident raised issues of “informed consent” and increased public criticism of medical paternalism. The emphasis, as the Donaldson Report into the practice suggests, was on “taking, retention and making sure people don’t object. It isn’t about asking people. It isn’t about seeking permission. It isn’t about donation. It should be more in the territory of a relationship based on a gift for which we feel and express gratitude” (Boseley, *The Guardian* Wednesday 31 January, 2001: 4). The “retention of organs” affair unquestionably demonstrated the inadequacy of the 1961 Human Tissue Act regarding issues of informed consent. The Donaldson Report (2001) recommends the

law be changed so there is positive agreement to post-mortems as opposed to the absence of refusal. As the same principle stated in the 1961 Human Tissue Act informs aspects of the legalities of organ donation (i.e. health professionals seek to ascertain the relatives' "lack of objection" prior to organ transplantation) it is likely this also will be amended. As yet, it is too soon to say as relevant statistics are not yet available, but initial media reports suggest the retention of organs scandal, at least in the short term, will provoke a "crisis" with a significant drop in donation rates.⁸ This thereby demonstrates the importance of public confidence in the manner in which the organs are procured.

Human Organ Transplants Act 1989

The 1989 Human Organ Transplant Act supersedes the 1961 Human Tissue Act, and was introduced following reports from the British media concerning trafficking in organs. In 1989, the British Parliament passed a law making it a "criminal offence to give or receive money for supplying organs of either a living or dead person." The 1961 Tissue Act had already deemed it unethical for medical personnel to be involved in any human organ commerce. The following incident was to set the agenda:

Last summer Colin Benton died after receiving a kidney transplant at a private London hospital. Several months later ... his case made headlines throughout Britain when his widow disclosed that her husband's kidney transplant had come from a Turkish citizen who was paid three thousand three hundred dollars to fly to Britain to donate the organ ... One investigation led in May to the conviction and imprisonment in Turkey of a fifty-five year old Tunc Kunter, the kidney broker who recruited the Turkish donor for Mr. Benton's operation. Two London doctors are [also] being investigated by the British Medical Council for their roles in the Benton operation (Brahms 1989: 285).

Consequently the introduction of the 1989 Organ Transplant Act prohibited the sale of organs. It states that:

1. - (1) A person is guilty of an offence in Great Britain if he (a) makes or receives payment for the supply of, or for an offer to supply an organ which has been or is to be

⁷ There are perhaps several reasons why the scandal surfaced at the moment it did. First, a less deferential attitude to the medical profession, second, a growing realisation of the commercial properties of the body and its parts and, finally, a symbolic value and emphasis on respecting the dead person's body.

⁸ The Royal Brompton Hospital and Birmingham's Queen Elizabeth did not carry out any transplants for 10 days following the publication of the extent to which organs had been retained (Templeton, *The Sunday Herald*, 4 February 2001).

removed from a dead or living person and is intended to be transplanted into another person.

Implicitly, UK legislation thereby legislates in favour of the voluntary, "opting-in" system currently in place. Any changes to the way that organs are procured (to be discussed below in Alternative Methods of Procurement) will thereby require changes in legislation.

Public Opinion

The legislation currently in place reflects the positive attitude the British public has towards organ donation and transplantation. The UK has a voluntary system of donation based on the donor card, first introduced as a kidney donor card in February 1971. In the early eighties, the card changed to a multi-organ donor card and the Department of Health has since issued around a hundred and fifteen million (UKTSSA 1997). The NHS Donor Register was introduced on 6 October 1994, by the then Parliamentary Secretary of State for Health, Tom Sackville, and by 1999, the number of individuals on the register was approximately 8 million (UKTSSA 1999: 3). It was hoped, by increasing the opportunities for registration and providing a record of the donor's intention, this would make it easier for relatives to agree to donation. Potential donors can also register (or remove their names) by post, when joining a new GP, and by an application for a driving licence. All data is downloaded to the Registry based at the United Kingdom Transplant Support Service Authority in Bristol. The information is then made available, twenty four hours a day, to transplant co-ordinators in the hope this will provide evidence to relatives of the donor's wishes, thus expecting to significantly reduce the number of relatives refusing donation (UKTSSA 1994). As yet, it is too early to gauge the effectiveness of the register on the UK donation rate.

The British Kidney Patient Association commissioned a yearly survey of attitudes towards organ donation and the donor card (British Kidney Patient Association, Transplant Survey, 4-10 May 1994, 1-6 November 1995, 16-20 May 1997, 5-11 November 1998).⁹ Where comparable, the results show there is little change in trends over the years 1994 - 1998. For example, in 1994, 67% of men and 66% of women would be willing to donate their kidneys after death, in 1998 the numbers increased

⁹ The sampling is representative of the adult population in Great Britain is weighted to give the correct proportion by sex, age, class, car ownership and home tenure.

slightly, to 71% and 72% respectively. There is virtually no difference between genders regarding willingness to donate organs.

From the 1994 study onwards, however, the findings demonstrated age and socio-economic grouping (SEG) of the respondent were significant in donation refusal. Of the 65 plus age band, nearly 32% would refuse donation and 20% of SEG D/E (B.K.P.A 1994). The 1998 B.K.P.A results indicated the refusal rate remains relatively unchanged: 30% of the 65 plus, and 25% of Class D/E. Consent rates also increase in those with higher levels of education (Gallup 1993).

Research in the States and in Britain also shows that levels of consent vary by ethnicity (Gallup 1993, Burroughs *et al.* 1998, BACCN/UKTCA 1995). For example, in Britain the BACCN/UKTCA study (1995) demonstrates families of Black Caribbean, Indian, Pakistani and Bangladeshi origin are more likely to refuse an organ donation request (48%, 43% 57%, and 67% respectively, compared with a refusal rate of 31% of Caucasian families). Neerja Jain, a transplant co-ordinator in Birmingham recently began a study into the South Asian community's attitudes towards organ donation and transplantation (Organ Donation and Transplantation: The Multi-Faith Perspective Conference, 20 March 2000). Given the increase in this community of end-stage renal failure¹⁰ and the importance of a close match in order for a kidney transplant to be successful, this programme is designed to encourage the South Asian community to consider organ donation, both living and cadaveric.

Lack of Attitude Translated into Behaviour

Trends from the B.K.P.A. study demonstrate positive attitudes towards organ donation are not necessarily being translated into behaviour. In 1994, 65% of men and 56% of women did not carry a donor card. In 1998, this increased with approximately 80% of men and 68% of women not carrying a donor card (though this decrease in donor card ownership may in part be due to the introduction of the National Organ Donor Scheme). Studies have shown that if the relatives know that the deceased had a donor card, they will generally not object to organ donation taking place (King's Fund Institute 1994). In the absence of a donor card, the families' own views will inevitably come into the decision, with the outcome that nearly 30% will refuse donation (BACCN/UKTCA 1995, Gore *et al.* 1991). The donor card is a legal document, as outlined in the 1961 Human

¹⁰ Patients of Asian and Caribbean origin are more likely to require a kidney transplant, more likely to suffer from non insulin dependent diabetes and have a high incidence of hypertension in their communities.

Tissue Act, but out of respect for the feelings of the next-of-kin, the physicians will always ask permission. This has led to some arguing that:

You could die with an organ-donor card in every pocket, and another one pasted on your forehead, and still no one would touch you if your current or separated but not divorced spouse, son or daughter twenty-one years of age or older, parent, brother or sister twenty-one years of age or older, or guardian, in that order, said no ... If you want to be an organ donor, carrying a card is much less important than making sure your relatives know your wishes (Owen quoted in Iserson 1994).

The relatives are asked on the basis that they would know the views of the potential donor. Who the medical profession approaches for permission demonstrates hidden assumptions about family structure, and perceptions of legitimate decision-makers within the family. Apparently, a “separated but not divorced” spouse has more say in the decision to donate or not, than a son/daughter and/or parent. Whether or not this results in familial conflict is unknown, as little research has been conducted into the role of family dynamics and effects on the organ donation decision. Available evidence will be outlined in Chapter 3, discussing whether and how family dynamics influence the decision to donate or not.

Religious views on Organ transplantation and Donation

Though little is known about the impact of family dynamics, studies have shown that religious objections to organ donation only account for approximately 7% of the refusal rate (BACCN/UKTCA 1995). The religious groups most likely to refuse are Jehovah’s Witnesses, closely followed by Sikh, Greek Orthodox and Muslim denominations, due to beliefs in how the body should be treated in the after-life (BACCN/UKTCA 1995: 12). By emphasising organ donation as an altruistic, giving, other-motivated act, most representatives of major religions are in favour of organ transplantation. Evidentially, at a recent conference held in Bradford, “Organ Donation and Transplantation: The Multi-Faith Perspective” (20 March 2000), distinguished members of religious communities from Judaism, Islam, Hinduism, Sikhism and Buddhism all suggested organ donation was congruent with their religious beliefs. All religious representatives attending were careful to stress organ donation and the saving of another’s life prevailed over respect for the dead body. All speakers acknowledged there were differences of opinion within each of their individual faiths, whilst simultaneously stressing organ donation as an action that saves lives, over-rides any other religious objections such as “honour the dead” and

“respecting the integrity of the dead body.” For example, the Chair of the Muslim Council, Dr M. A. Zaki Badawi, brought attention to a “fatwa that actually saves lives” within the Muslim community regarding donation. The hierarchy of Shai’rah, which states an individual should save lives by whatever means, thereby overrides the Muslim respect for the dead which, he says, is applicable to both Shi’ite and Sunni followers.¹¹

Similarly, in Judaism, the “pikkuah nefesh,” the commandment to save life, subsumes the “kavod ha-met,” the honour due to the dead. Potential problems exist, however, such as the delaying of the burying of the dead and caring for the recipient on the Sabbath (Professor David Katz, UCL Medical School, London). The Christian viewpoint, stated quite forcefully at the conference by the Bishop of Rochester, is “organ transplantation is an intermediary technology till other ethically acceptable alternatives are introduced. Carving up dead bodies does not maximise respect for the dead.”

Individual Choice, Religion and Organ Donation

The contributions from representatives not in attendance, Jehovah’s Witnesses, and members of Christian Scientists, would have proved significant. Though Christian Scientists do not have a specific position regarding organ donation and transplantation, they normally rely on spiritual means of healing and, therefore, organ transplantation is considered a matter of individual choice (organdonation.org/religion.html). Jehovah’s Witnesses, according to the Watch Tower Society, also believe it is a matter for the individual to decide. It is assumed they are opposed to organ donation because of beliefs against receiving blood transfusions. However, this only means all blood must be removed from the organs and tissues before being transplanted, and it would not be acceptable for the donor to receive blood during recovery at the post-transplant stage (organdonation.org/religion.html). “Bloodless” transplants, by combining existing techniques and specialised drugs, increases the risk for the recipient, but are beneficial in that there is less risk of mismatching blood types and catching infections, and costs are lowered (a pint of blood costs approximately £100 and five to six pints can be used).

Religious Objections

The only two identified groups that have significant objections regarding organ transplantation are Romany Gypsies and those belonging to the Japanese religion of Shinto. In Shinto, the dead body is considered to be impure and dangerous, and the Japanese are wary of causing injury to it. Families are often concerned about harming the

¹¹ For further discussion of differences within the Muslim community about organ transplantation see Gatrad, A.R. (1994).

itai - the relationship between the dead body and the bereaved (organdonation.org/religion.html). Romany Gypsies do not have a formalised religion as such, though they share a folk belief that tends to oppose organ donation. This opposition stems from a belief that one-year after death, the soul retraces its steps and the body must remain intact because the soul maintains its physical shape (organdonation.org/religion.html). Thus, it would appear it is not always religion *per se* that affects donation, rather religiously informed cultural beliefs regarding the status of the body and “soul” after death.

From the discussion above, it would appear there are widespread positive attitudes towards organ donation, although these are not being translated into behaviour. There are subtle inter-group differences within the UK population. On a macro level, donation appears more popular within the white, educated, upper classes and less so in other groups. Though such demographic information is useful, it is likely each group is not homogenous, and it is unclear how this translates into refusal and agreement rates when faced with an organ donation request, a matter that shall be returned to in Chapter 3.

METHODS OF PROCUREMENT: CADAVERIC DONATION

Required Request

Because of the perceived failure to harness popular opinion into concrete donations, some authors have focussed on the roles of health professionals in negotiating organ donation. “Required request” is an approach that centres on the role of the physicians. Arthur Caplan (quoted in King’s Fund Institute Report [1984] 1994) first introduced the concept, making it mandatory for physicians to ask the next of kin whether they wanted to donate organs. Required request is a system used in the United States in conjunction with voluntary consent. The British Medical Association’s “Guidelines on the Transplant of Tissues and Organs” (British Medical Association Guidelines 1996, Personal Communication) rejects the implementation of required request, as it would not allow the physician any scope for sensitivity regarding the relatives’ religious beliefs or personal objections. As such, this only serves to cause additional pain to the recently bereaved. Moreover, as mentioned previously, the audit of ICU’s carried out in 1989 by Gore *et al.* (1991) found in only 6% of cases no request was made.

Presumed Consent

Like Britain and the United States, most countries allow individuals to voluntarily consent or colloquially “opt in” to organ donation. Yet there are more than thirteen

countries that have a “presumed consent” or “opt out” law, based on the assumption individuals are willing to donate their organs unless they have registered an objection otherwise. There are two versions, a “strong” one that ignores relatives’ objections and takes the organs regardless, and a “soft” version where objections are taken into consideration. Recently, the British Medical Association changed their pro-stance towards voluntary donation, to one of a soft presumed consent (Trueman, *The Scotsman*, April 24 2000). The issue is not uncontroversial in Britain, and several bodies such as the Royal College of Surgeons and the British Transplant Society remain unconvinced (Boseley *The Guardian*, July 9 1999: 3). The Royal College of Nursing is also against such a change, voting to maintain the status quo (Trueman, *The Scotsman*, April 24 2000). At the Royal College of Nursing Conference on 3 April 1999, 69.5% voted against opt-out (Johnson, D. 31 March 2000, Personal communication). At present, the Government has rejected the BMA’s presumed consent proposals, and has no plans to introduce changes (news.bbc.co.uk/1/hi/english/health/newsid-396000/396430.stm). Table 6, documents the legislation of selected countries, highlighting both “soft” and “strong” versions of presumed consent.

Table 6 - Countries' Legislation for Procuring Organs

Country	Legislation
Australia	Voluntary Consent
Austria	Presumed consent - 'strong'
Belgium	Presumed consent
Cyprus	Presumed consent
Denmark	Presumed consent - 'strong'
Finland	Presumed consent
France	Presumed consent
Germany	voluntary (non-presumed) consent (Law approved 1997)
Greece	Presumed consent- but not practised
Hungary	Presumed consent
Italy	Presumed consent- 'strong' but not practised
Irish Republic	Voluntary consent
Japan *	Voluntary consent
The Netherlands	voluntary (non-presumed) consent (Law approved 1997)
New Zealand	Voluntary consent
Norway	Voluntary consent
Portugal	Presumed consent- but not practised
Singapore	Presumed consent - 'strong'
Spain	Presumed consent- but not practised
Sweden	Presumed consent
Switzerland	Presumed consent - 'strong'/ voluntary consent (depending on canton)
United Kingdom	Voluntary consent
United States of America	Voluntary consent (with required request)

* Japan now recognises brain stem death (new law passed October 16 1997) and cadaveric donation is now both possible/legal in that country.

Source: O'Neill (2001).

As seen in Table 6, countries such as Spain, Greece and Portugal have opting-out legislation, but do not necessarily practise it. Sweden, Hungary, Italy, Finland, France and Belgium all have soft versions of presumed consent, whilst Singapore, Denmark and Austria have stronger versions. Both versions of presumed consent have shown a modest degree of success. Belgium and Austria, are held up as the ideal models, with organ recovery more than doubling following implementation of presumed consent legislation.

Social and Ethical Arguments Against Presumed Consent

Those that object to presumed consent legislation argue there is always the possibility of “false positives” that is, a risk of removing organs against the wishes of the donor. Ultimately, “[N]o presumed consent legislation can possible guarantee that the wishes of all concerned will be respected” (King’s Fund Institute Report 1994: 61). There may be sections of the population either unaware of the legislation or unable to understand it (King’s Fund Institute Report 1994: 61). Indeed, what of the wishes of the family? A “soft” version of opting-out, which takes into account the wishes of the family, seems essentially no different to the present system of opting-in. In both cases, voluntary donation and “soft” presumed consent, the final decision is vetoed by the family so if a soft version of presumed consent was introduced then this would not diminish the 30% refusal rate of relatives (BACCN/UKTCA1995, Gore *et al.* 1991). On the other hand, a “strong” version of presumed consent is more controversial. Some doctors may be unwilling to over-ride objections from relatives, thereby negating the impact of the legislation. Further, a hard version of presumed consent could easily result in offending the sensibilities of the bereaved relative. In France, donation rates dropped after the parents of Christopher Tesniere lodged a complaint in court objecting to the removal of their son’s eyes. The publicity that resulted from the case led to shortages across the country (Patel 1993: 12). The conference of European Health Ministers commented that:

... the role of the family in deciding on organ removal is much more important in cases of presumed consent than in cases of express consent. In the latter case the sentimental objections of the family have to be weighed against the legal rights of the deceased who has willed the organ donation. In the case of presumed consent the family’s express objection weighs more heavily against the presumed consent of the deceased ... In practice therefore whether consent is express or presumed, the final decision rests to a very large extent with the family of the deceased

(Conference of European Health Ministers [1987] quoted in King's Fund Institute 1994: 62).

Offending the sensibilities of grieving relatives and ignoring individual rights has an impact on the relationship between the medical profession and the British public, as Alder Hey demonstrated. Presumed consent might well increase the organ donation rate but it may have long term consequences for trust and respect between doctor and patient. The paradox is with increasing emphasis placed on the organ shortage, the more plausible stories and urban legends are regarding the existence of underground trading in organ donation (King's Fund Institute 1994: 41).¹²

Public Opinion and Presumed Consent

There is limited evidence regarding public opinion on the introduction of presumed consent legislation. In the United States, the UNOS Ad Hoc Donations Committee conducted a telephone poll of 801 individuals in January 1991 (National Kidney Foundation, United Network for Organ Sharing, OrganDonationStudy UNOS1993/gopher://info.med.yale.edu/00/Disciplines/DISCIPLINE/Transplant/Ethics/ethic2txt). Results indicated 38% of the American population were in agreement with presumed consent, 55% against and 7% undecided. A study conducted in 1998 by the Department of Health, attested to the UK public's support for an opt-in system. Fifty per cent of the sample stated they were in favour of the current system, compared to 28% in favour of "opt-out" (Johnson, D. 31 March 2000, Personal communication). However, these results contrast with a recent poll conducted in Scotland (System Three, *The Herald* April 2000). Nine hundred and ninety one adults were asked: "Would you support or oppose a change in the rules governing organ donation proposed by the British Medical Association, which would require people to opt out of giving their organs as opposed to the present system of opting-in?" Overall exactly half the sample (50%) supported a change to opting-out, compared with 36% who were opposed. If the 14% undecided are excluded, this results in 59%: 41% ratio in favour of change. Unfortunately, the poll did not discriminate between the two versions of presumed consent, so it is difficult to gauge exactly what the respondents were agreeing to. Moreover, there seems some level of respondent uncertainty regarding what was meant by the term "opting-out" (14%) concentrated among older respondents and lower socio-economic groups.

¹² Urban myths regarding organ procurement, generally revolve around the following theme; "a young man goes out to a night club and meets a girl there. They have a few drinks and he returns to her flat where he loses consciousness. He awakes in the bath with a note to say that he should not move but call the hospital immediately. On examination at the

Factors that Affect Success of Presumed Consent legislation

Finally, possible transgressions of public confidence may be made at the expense of a procedure whose efficacy is unknown: there are factors that hinder the success rate of presumed consent systems. For example, it is significant that the four countries that have high transplanting activity also have high road death rates per million of the population (Austria, Spain, Belgium and France) and presumed consent legislation. As can be seen from Table 7, there appears to be a relationship between a high mortality rate from road traffic accidents and the rate of donation, and this gives a false representation of opting-out legislation.

Table 7 - Road Death per million population (1990) and presumed consent legislation

Country	Road Death pmp	Presumed Consent Legislation
Norway*	79	YES
Sweden	91	
UK	94	
Denmark	124	
Germany	130	
Finland	130	YES
Australia	136	
Switzerland	140	
Canada	148	
USA	177	
France	200	YES
Belgium	202	YES
Austria	205	YES
New Zealand	215	
Netherlands	215	
Spain	230	YES
Portugal	310	

*Norway has high levels of donation despite a low mortality rate from RTA due to increases in the level of living donation.

Source: King's Fund Institute (1994: 26).

hospital it is found that one of his kidneys have been removed." These "urban myths" demonstrate the existence of public

As stated previously, in 1999, the UK had its lowest incidence of mortality from road traffic accidents since 1926 and subsequently, “there is a strong suggestion that road death rates have a significant influence on transplant rates” (King’s Fund Institute Report 1994: 27). Then, regardless of whether any version of presumed consent was introduced, this would not make a significant difference in donation rates, as the sources themselves are in decline.

The “Spanish Model”

Since 1989, regardless of procurement system, the European donor rate has remained immobile, with rates typically remaining between fifteen and twenty per million population (Scott 1993) suggestive of a plateau in donation rates (Table 8).

Table 8 - Organ Donation and Transplant Activity per million population (pmp) in Europe 1997

	<u>Eurotransplant*</u>	<u>France</u>	<u>Spain</u>	<u>UK/Republic of Ireland</u>
Cadaveric Donors	1578	970	1334	815
pmp	13.8	16.2	33.8	13.0

* Includes countries such as Germany, Austria, Belgium, Luxembourg and the Netherlands.

Source: United Kingdom Transplant Support Services (1999: 5).

As can be seen from Table 8, Spain is the only exception to this plateau, with more than double the donation rate per million of the population.¹³ There has been an immense amount of interest in the Spanish case in recent years, and representatives from the UK transplant co-ordinators association (UKTCA) are impressed with the Spanish system of an extended transplant co-ordinator network and national training programme (Fabre *et al.* 1995: 30). In Britain, as elsewhere in Europe, the transplant co-ordinators operate at the regional level working close to transplant units. In 1990, Spain introduced co-ordinators at all donating hospitals. In 1989, there were 25 co-ordinating teams and by

distrust about the means in which the organs are procured, and any planned change in policy might attend to this.

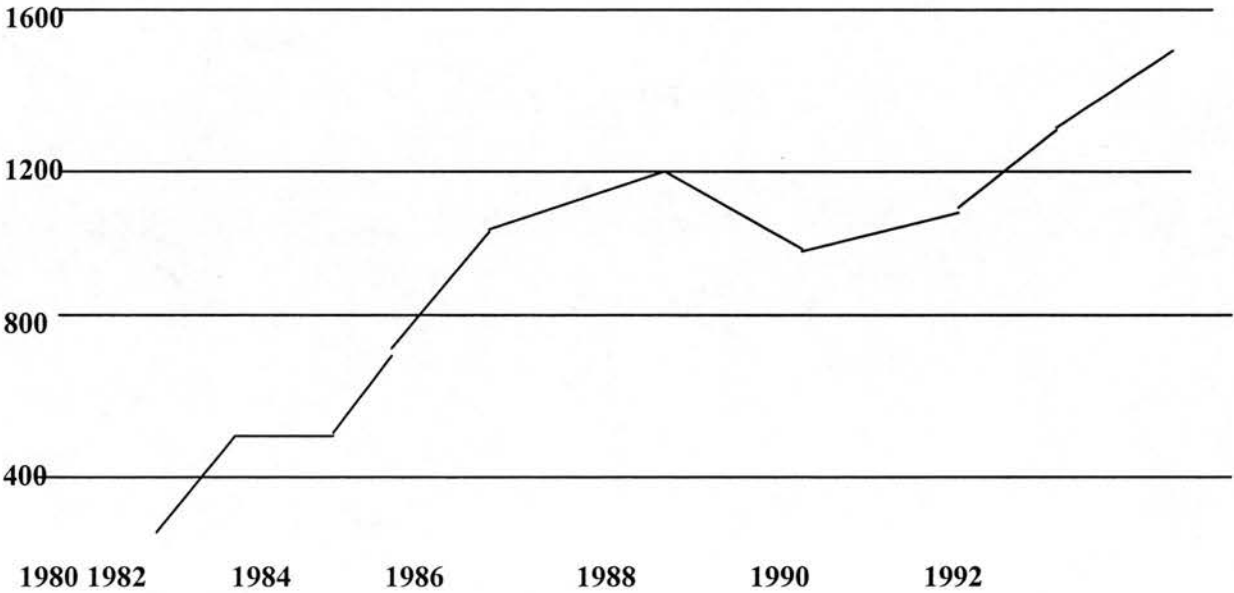
¹³ Using per million population as a criterion to assess donation rates may offer an inaccurate picture - donation rates are dependent on the number of brain stem deaths occurring within a country and not a country’s population.

1992 this figure had increased to 118 (Matesanz *et al.* 1994: 283). The co-ordinators work part-time, and then spend the rest of the time in their speciality, usually in intensive care or nephrology (King's Fund Institute Report 1994). This integrates intensive care and nephrology work with organ procurement and differs from the UK:

... education and liaison with intensive care staff is of prime importance. In Spain this process can be more or less continuous with units having dedicated part-time or whole time staff on site. Under such a system, local hospitals without transplant units are likely to be sympathetic and well-informed as to the needs and importance of the transplant procurement process (King's Fund Institute Report 1994: 50).

Spain also has a national co-ordinating body, the *Organisacione Nacional de Transplante* (ONT) that monitors donation rates and oversees policy at three levels, the local or hospital, regional and national (Matesanz 1994: 282). Cumulatively, this has resulted in a significant rise in donation rates, as can be seen from Table 9.

Table 9 - Kidney Transplants Undertaken (Spain 1980 – 1992)



Source: King's Fund Institute (1994: 51).

O'Neill (1998) argues that applying the Spanish model to other countries (in his case Australia) ignores the variations in cultural, social and structural differences. For example, all Spanish transplant co-ordinators are doctors, paid a nominal fee for their work in organ procurement. This, argues O'Neill, is likely to lead to relatively new and

inexperienced members of the medical profession being attracted to organ transplantation. “If so, identification of potential donors rests with relatively inexperienced and junior doctors, creating the real possibility of misdiagnosis of brain stem death (a necessary criterion for donation) and the false identification of potential donors” (1998: 6). Further, the Spanish system is dependent on donor identification, as opposed to the British system of donor referral. Inherent to the identification of donors, is a danger the public will perceive doctors as only being interested in patients as possible organ donors, rather than requiring treatment.

A further cause for concern is the employment of “persuasive strategies by the interviewer” as recommended by Santiago and Gomez (1996). Here, they outline strategies to change a negative response, demonstrating that in approximately 70% of cases, clinical staff managed to persuade Spanish families to change their decision. However, the authors do not discuss the ethics of using such persuasive techniques that closely resemble the use of pressure, or whether the families came to regret their decision.

LIVING DONORS

Regardless of debates regarding the effectiveness and acceptability of other systems, arguably the crucial issue is a long-term decline in available cadaveric sources. Preliminary data from 1999, show a 2% decrease in the number of cadaveric donors, a decrease that may have been largely offset by an increase in living donation of 8% (UKTSSA 1999: 10).

Living donors can donate one of their paired organs such as the kidneys, parts of the liver (the liver can regenerate to a certain extent) and replenishable tissues can be transplanted from living donors. The chance of rejection is lessened as donor and recipient are likely to be genetically related. Hearts from living donors are the result of “domino” heart and lung transplants where the recipient’s healthy heart is transplanted into another. A portion of the lungs can also be taken from a living donor, a contentious procedure that potentially compromises the donor’s health, as lung capacity is significantly reduced. Table 10 is a breakdown of organs transplanted from living donors in 1999.

Table 10 - Organs donated for transplant from living donors, 1 January - 31 December 1999

Organ	Country of Donation				Total
	England	Wales	Scotland	N Ireland *	
Kidney	230	10	27	2	269
Heart	124	-	-	-	124
Lung(s)	4	-	-	-	4
Liver	13	-	-	-	13
<i>Total</i>	<i>371</i>	<i>10</i>	<i>27</i>	<i>2</i>	<i>410</i>

* Included Republic of Ireland.

Source: United Kingdom Transplant Support Services (1999).

Living donation is fraught with difficulties, both for the families and the health professionals involved. Primarily, it compromises the Hippocratic oath of *primum non nocere* – first do no harm. Thomas Starzl, an American transplant surgeon who pioneered liver transplants, stated as early as 1972, that “the most compelling argument against living donation is that it is not completely safe for the donor” (Scott 1993: 145). Starzl argues that, “an estimated twenty donors have died from the removal of one kidney” (Starzl 1985: 5) and he refuses to perform liver transplants using live donors. As in any operation, there is always a risk, and the reported mortality rate for living donors is, in the short term 0.05%, and long term 0.07% (Simmons, Klein and Simmons 1987: 39).

In living organ donation, an individual, usually a family member, donates a kidney to the recipient. As mentioned, the 1989 Organ Transplant Act makes it an offence, unless specific safeguards are followed, for organ donation to occur between non-genetically related individuals. However, with the realisation that this precluded kin relations such as husband and wife, the regulatory body ULTRA - Unrelated Live Transplant Regulatory Authority – was set up to monitor unrelated living donors. One of the first cases of unrelated donation took place in November 1999, when a British man donated a

lobe of his lung to a ten year old American girl suffering from cystic fibrosis ('Briton Gives Part of Lung to Help Save 10-year-old' *The Herald*, November 25, 1999).¹⁴

In Britain, at least nineteen people offered to donate a kidney to Graham Reeves, whose own healthy kidney was removed and his diseased one left, in a mix-up that occurred at Morriston Hospital, Swansea (*The Guardian* February 3 2000). Unfortunately, Mr Reeves died shortly afterwards. Although most of the live donors until 1994 had been confined to parents and siblings, it is likely that this would be expanded to include spouses, due to the findings of a report that demonstrated the graft was as good as one from a related donor (*The Guardian* February 3 2000). In the States, some 699 spousal transplants were conducted in the last three years, (1997-1999) with a 74% success rate (news.bbc.co.uk/1/health/mewsid-265000/265142.stm). At present, the UK living donor kidney transplants is equivalent to 4.3 per million population (pmp), well below that of other countries such as Denmark, Sweden and Norway, which cumulatively have a 9.7 pmp (UKTSSA 1999: 5). The Report of the Working Party on Organ Donation (Fabre *et al.* 1995) suggests 88% of intensive care unit directors believe expanding living donation would make a significant impact on kidney donor rates (1995: 31). It would appear one way of reducing the organ shortage is to utilise living donation to a greater extent, though little is known about the social, ethical and psychological implications for the families and health care professionals involved.

XENOTRANSPLANTATION

An alternative means of increasing the supply of organs for transplantation is to look to other non-human sources. It is hoped, xenotransplantation, would eliminate, or at least alleviate the shortage of organs, and refers to the practice of implanting organs or tissue from one species into another. Proponents argue, xenotransplantation will avoid the need to consult relatives at a highly distressing time, and that enough animals could be reared to overcome the present shortage (Nuffield Council on Bioethics 1996: 7). It is not an entirely new concept; animal-to-human transplants were common in early transplant work, and xenografts have been attempted since 1905 (Hanson, quoted in Scott 1993: 152). Pig's tissues and valves are also commonly used in open-heart surgery, and for the last thirty years, insulin from pigs is used to treat diabetes (Nuffield Council on Bioethics 1996: 6). The first to attempt solid organ cross-species transplantation may have been Dr James Hardy, of the University of Mississippi Medical Centre. In 1964, he grafted a

¹⁴ Unfortunately Lisa Ostrovsky died shortly afterwards.

chimpanzee’s heart into a sixty-four-year old man. The heart worked for ninety minutes before the patient’s death (Singer 1994: 164).

In 1984, the case of Baby Fae received intense media coverage, when a baboon’s heart was transferred into a 15 day old infant. The girl survived for 20 days. Like other cases in the early history of organ transplantation, this was surrounded by controversy, with some medical professionals arguing an attempt was not made to find a human donor. Singer (1994: 164) suggests the case “met with an almost universal chorus of disapproval, from the general public, news commentators and from bio-ethicists. Many thought it was wrong because it amounted to human experimentation.” Table 11, gives examples of the major xenotransplantation procedures involving primates and other animals, and the survival rate of recipients.

Table 11 - Examples of the major xenotransplantation procedures involving human recipients (1994)

Primates
All operations took place in the US.
1964 Six patients received baboon kidneys. All died within two months.
1984 Baby Fae received baboon liver and survived 20 days
1995 AIDS patient received a baboon marrow transplant in December.
Other Animals
1964 First UK pig heart valve transplant took place. Now a routine operation.
1968 Patient received sheep heart and died instantly.
1992 Patient received pig heart and survived less than 24 hours.
1994 Ten Swedish diabetic patients received pig foetal islet cells. In four patients, the pig cells survived up to 14 months. Insulin produced at extremely low levels.

Source: Nuffield Council on Bioethics (1996: 27).

Cloning

As with human organ transplantation, xenotransplantation suffers from the ability of the recipient’s immune system to reject matter perceived as “not self.” Cloning offers the possibility of dealing with the problem of rejection. Cloning is the nuclear transfer and the ability to derive live animals from cultured cells. In treating leukaemia, for example,

a few skin cells would be taken from the patient and converted in the laboratory into white blood cells. The same procedure could work for strokes, Parkinson's disease, diabetes and heart attacks. Repeating the process further with animal cells results in identical animals. If the animal cells are genetically modified, then this will result in genetically modified animals.

Cloning a genetically modified pig, known as a transgenic pig, carrying human genes may provide a means of dealing with the problem of rejection. Transgenic pigs are being developed in order to meet the shortage of human organs. Pigs are thought to be a more viable alternative to chimpanzees and baboons because the animals are closer in size to humans and are easier to breed in large numbers (news.bbc.co.uk/1/hi/english/sci/tech/newsid-424000/424956.stm). The transgenic pigs contain an added human protein that coats the pig's tissue; a camouflage, it is hoped, that will stop the rejection of the transplanted heart or kidney. A major drawback to xenotransplantation seems to be uncertainty around "zoonosis," the transfer of potentially harmful diseases to humans from pigs (Evan, *The Guardian* Wednesday 2 May 1998: 3). The United Kingdom Xenotransplantation Interim Regulatory Authority gave permission to carry out trials, and preliminary results suggest pig organs may be safe to use in human transplants (news.bbc.co.uk/1/hi/english/sci/tech/newsid-424000/424956.stm). In a study of 160 patients treated with various pigs' living tissues, initial findings demonstrate the danger of zoonosis appears groundless. However, this study examined only pig's tissue and not organs, and therefore may have limited applicability. It is debatable whether negative results should be taken as proof of the absence of a virus as it can also be construed as a failure to find it (news.bbc.co.uk/1/hi/english/sci/tech/newsid-424000/424956.stm).¹⁵

A recent report by the UKXTIRA set out guidelines on the "monitoring and surveillance of potential infections associated with xeno-transplantation" (Woolf, *The Daily Telegraph*, October 25 1999). In this report, it was suggested contracts will be made with patients who receive pigs' hearts or lungs, requiring them to use "barrier contraception consistently and for life," and they should agree never to donate blood. Health monitoring teams would regularly check "household members and sexual partners and

¹⁵ Because of fears regarding the transmission of potentially dangerous new viruses, a moratorium has been introduced in the UK, effectively banning any research using animal cells (Christie B, *Scotland on Sunday* May 30 1999).

others with whom the transplant recipient may engage in activities in which bodily fluids may be exchanged” (Woolf, *The Daily Telegraph*, October 25 1999).¹⁶

THE SOCIOLOGICAL ISSUES OF CADAVERIC, LIVING AND ANIMAL-TO-HUMAN DONATION

Cadaveric Donation- Social Groups and Systems

In this last section, attention turns to the ethical, social and practical issues, associated with cadaveric, living and animal transplants. For example, the success of cadaveric donation relies on public confidence. Organ donation, perhaps unlike any other procedure, depends on the establishment of trust and openness between the public and the medical professional. Arguably, any shift in the public’s perception of the trustworthiness of the medical profession will have significant repercussions for the donation rate. Presumed consent legislation is not likely to be introduced when the current climate already suggests that there is resentment at the “taking” of organs and suspicion directed at the medical profession. The likelihood of any change in the legislation is slim given the current climate post - Alder Hey. Equally, regarding the introduction of the Spanish model, O’Neill concludes that:

... whilst the increase in the donor rate ... is impressive it should not blind us to the fact that any system employed to increase organ donation must be socially and culturally acceptable. It remains to be seen whether adoption of the Spanish model of organ donation, which focuses primarily upon identification of potential donors prior to their death, will, in the long term be compatible with Australian cultural values (1998: 10).

As mentioned, the British system is based on a donor *referral* system not that of donor *identification*. There is perhaps no other medical procedure that depends to such an extent on social and cultural acceptability. If health care professionals are perceived to be more interested in the person as a potential donor, then public confidence in organ transplantation will drop. Further, both the United Kingdom and the United States have voluntary consent systems, compatible with their widespread liberal ideologies and emphasis on individual rights. Such liberal individualism puts the rights of the individual first, before that of the community. Such societal arrangements assume the individual or

¹⁶ The reason why pigs are cloned as opposed to organs is, as Dr Griffin of the Roslin Institute (of cloned sheep “Dolly” fame) explains, because it is not possible for organs to be grown from cells as “hearts and kidneys are very complicated and the prospect that they can somehow “self-assemble” in a large test tube seems vanishingly small” (Griffin, H. *The Sunday Post*, 22 November 1998: 13).

their family has control over the body, to a greater degree than that of society. Similarly, those societies that have strong state interventions in the affairs of the population are more likely to accept a presumed consent system. Austria, for example, has had compulsory post-mortems for all deaths in hospital, and therefore the removal of organs under presumed consent legislation might be considered as simply an extension of this mandatory role.

Yet the way that organs are procured does not just reflect larger social systems and ethos, but can also demonstrate smaller group interactions and beliefs. Views on organ transplantation and donation differ at the macro and micro levels. For example, although the vast majority of religious and ethnic groups are supportive of organ donation, the importance a particular religion places on the way the dead body is treated, can contradict the emphasis placed on saving another's life. In other words, the cultural connotations of the transplantation procedure can conflict with the valued social behaviour of donating an organ. In addition to such cultural beliefs, language barriers and a perceived racism in the organ transplantation system that organs are allocated to the white majority (see Exley *et al.* 1996 for further discussion), general institutional suspicion and lack of trust in the medical profession, can further alienate excluded groups.

Living Donation - Ethical and Social Dilemmas

A different set of social relationships, that is kinship networks, also results in differing perceptions of transplantation and donation rates. In related living donation, a powerful normative obligation to come to the aid of a family member exists, that not only subverts the principle of voluntariness cadaveric donation rests on, but anonymity between donor and recipient. In living donation the donor and recipient are, by definition, known to each other. Consequently, the strength of bonds that generally ties family members together implies a more obligatory system of relations. It is well documented in living donation, that when an individual requires a kidney, members of the family often approach the medical staff before they have a chance to make a request (Simmons, Klein and Simmons 1987) thereby raising issues about the level of "informed consent." Feminist writers have shown that women, either in a family or couple, who offer help are more likely to do so because of a "compulsory" altruism rather than a "voluntary" one (Gilligan 1982). One future area of research into living donation would be to ascertain whether mothers are more likely than fathers to donate to their children. The World Health Organisation report on Organ Transplantation (1991: 8) states that:

Organs for transplantation should be removed preferably from the bodies of deceased persons. However, adult living persons may donate organs, but in general such donors should be genetically related to the recipients... An organ may be removed from the body of an adult living donor for the purpose of transplantation if the donor gives free consent. The donor should be free of any undue influence and pressure and sufficiently informed to be able to understand and weigh the risks, benefits and consequence of consent.

There is, unfortunately, little information available regarding family dynamics and living donation, although research by Simmons, Klein and Simmons (1987) conducted in the States is useful. Existing research suggests that, although the majority of donors did not indicate they felt under any emotional stress or pressure about the decision, on the contrary, they benefited from being able to help a loved one, a minority did suffer from a high level of anxiety about the decision:

Brother donating to his sister:

... It's my conscience against my body. My conscience says I have to do this, and my body says no. I don't want to. Like when I called Gwen yesterday after I got here I was going to tell her better about the conflict I feel. She said, "You don't have to do it." I said, "I know I don't have to," and I said "Gwen, I don't want to do it. No one really wants to." She started to cry then and said "Then don't. I'll just die." God! What can I say?? I told her I'd never let her die, but I thought Bill [patient's son] should be first. He could do it ... (Simmons *et al.* 1987: 156).

Despite this, authors such as Evans (1992) come to the following conclusions regarding the living donation in the United States:

[If] living-related and living unrelated kidney donations were more aggressively pursued, the demand for kidney transplantation, could conceivably be met ... Of the 9560 kidney transplants performed in 1990, 18.5% involved living donors. In 1982, 31.3% of kidney transplants involved living donors. Based on current demand (i.e. 18, 592), it would clearly be undesirable if the ratio of living to cadaveric donor transplants decreased further (Evans [1992] quoted in Scott 1993: 147).

There is reluctance in this country to perform live donation between strangers, and a certain suspicion directed at the motives of an unrelated donor. Paul Lear, director of

transplantation at the North Bristol Hospitals Trust suggested, “I wouldn’t do it [an unrelated living transplant]. Maybe my views will change in a few years, but it’s very difficult for me to understand how a donor can get very much out of what they put themselves through if they don’t know the recipient” (Weale, *The Guardian*, November 30 1999: 5). Hidden within this statement, is an assumption the donor will receive some form of emotional reward from donating to a family member, which would not be forthcoming if an organ was donated to a stranger. Nonetheless, Evans (1989) argues the practice of limiting live organ donation to relatives actually precludes the possibility of putting into practice “true altruism” between strangers. He states, “altruism receives its highest expression in the absence of personal relationships - that is, when there can be no question of even emotional self-interest. The gift of an organ to a complete stranger, whose identity is concealed from the donor and from which the donor’s identity is concealed, seems worthy of respect” (1989: 19).

Social and Ethical Implications of Exchanging Body Parts

Inevitably, advances in medical technology are accompanied with new and often difficult dilemmas. Hand and face transplants raise a host of practical, ethical and social questions regarding the wisdom of such procedures. Clint Hallam, the recipient of the first hand to be transplanted asked for it to be removed after two years, following a serious rejection episode. The rejection, argued the doctors, was due to Hallam’s persistence in not following prescribed medication (Naysmith, *The Sunday Herald*, 4 February 2000: 3). Hallam, on the contrary argued, that “I’m convinced that there has come a stage, with the number of rejections that I have experienced, that my body or my mind has said ‘enough is enough’” (Naysmith, *The Sunday Herald*, 4 February 2000: 3). Hallam seemed to imply a “psychological rejection” was involved, a suggestion denied by medical professionals or amended to argue it followed physiological rejection. Other hand transplants, including the double hand transplant, are continuing successfully, raising questions not only about this individual case but whether those who “need” limbs more would be more willing to follow the stringent after-care regime.

Rejection is an intrinsic problem for recipients, and although Hallam’s hand was removed, in other transplants the risk of rejection and subsequent removal may be especially onerous. What are the psychological and physiological implications of removing a face? Even with the advent of immunological advances, what relatives are going to agree to the removal of their deceased’s face for donation? Moreover, is it ethical to perform an operation that, unlike other transplants, such as heart and lungs, is

arguably not life saving and involves an otherwise healthy patient spending the rest of their life on a powerful cocktail of immuno-suppressants?

Transplants occurring on the external surfaces of the body also raise the question of “self” and “not self.” The relationship between personal and corporeal identity becomes especially onerous and complex. For example, how will a patient be able to cope with the reminder that their hand/face is not actually theirs? The impermeability of bodily boundaries is also transgressed when parts of others are so easily exchanged with another. Could this have an unintended consequence of loosening the sense of individual corporeal existence? Part of how we know who we are as an individual, and how we are different to others, relies on our bodily disparity.

Protecting Boundaries

Animal to human transplants is, therefore, an extremely contentious and emotive issue. The possible personal effects of receiving a pig’s organs have as yet to be explored and may challenge notions of what it is to be “human.” Douglas in her seminal work “Purity and Danger” (1966) suggests “pollution behaviour is the reaction which condemns any object or idea likely to confuse or contradict cherished classifications” (1966: 36). Dirt, or rather uncleanness, is “matter out of place” something that may be out of synch with the supposed natural order therefore causing ambiguity and concern (1966: 36). Applying this analogy to xenotransplantation, although pigs or any other animal, may not necessarily be considered unclean, their usage in xenotransplantation challenges known schemata of what it is to be a “pig” and what it is to be “human.” More controversially, Douglas’s work may also be applied to “directed donation” where some sections of society are concerned with maintaining what they perceive as their group identity and boundaries. A case reported in the British media raised concern last year, when Northern General Hospital in Sheffield, accepted an organ from a donor family that stipulated it must only go to a white person. At that time, there were no regulatory mechanisms to stop the next-of-kin from attaching conditions to who should receive the organs. Since then, an inquiry into the incident has led to organisational changes within the British organ transplant organisation, UKTSSA and recommendations for clearer guidelines regarding directed donation in order to prevent such racism reoccurring (*The Guardian*, Wednesday 23 February 2000).

PPL Therapeutics, the company that cloned Dolly the sheep, argue pig-to-human transplants are becoming less of a public taboo (headlines.scotland.net Friday April 14

2000). Their managing director, Dr Ron James is exaggerating, however, when he argued the first operation would be met with “general joy.” For example, Birch and Michael (1998) object to xenotransplantation on the grounds:

We might consider the suffering of humans who are chronically ill with heart or kidney disease and who face an equally chronic shortage of organs: To what extent is the possibility of alleviating human suffering sufficient to justify raising animals in order to kill them for their organs? There is also the question of whether we consider it ethical not only to use animals for such purposes but also to deliberately create them (1998: 247).

While not denying this type of concern, most societies raise animals to kill them for sustenance, and there seems little difference between killing animals for meat or killing them for organs. Nevertheless, in the modern era, eating meat is a culturally ambivalent phenomenon. In 1945, there were approximately one hundred thousand vegetarians in the UK. In 1999, ten million people did not eat red meat and approximately four million were vegetarian or vegan (7% of the British population). At the present rate of growth, estimates suggest the UK will be completely vegetarian by 2030 (vegsoc.org/new/1999/nvw/99reasons.htm). Disregarding whether this is an accurate prediction, xenotransplantation is hardly going to be considered as “culturally neutral” in such a social context.¹⁷ As will be discussed in Chapter 5, “Organ Transplantation and Embodiment,” both donors and recipients are apt to “personify” the organs they give and receive. Some recipients, such as the aforementioned Clint Hallam, “psychologically reject” an organ leading to the question, “What form would such a reaction take if the donor was an animal”?

Singer (1992), a leading advocate of animal rights, argues using animals for xenotransplantation is a form of speciesism, akin to sexism and racism, and is premised on the grounds that to be a member of one group is superior to those not in that group. A member of the human race is regarded as being morally superior to all other species, i.e. animals, and therefore there is a perceived right to exploit them for the purposes of humankind. However, without going into the intricacies of Singer’s argument, at the end of his discussion he has to admit, if the choice is to be made between killing a baboon

¹⁷ In response to ethical concerns concerning cloning, President Clinton has announced a five-year moratorium on human cloning (Watts, *The Guardian*, Wednesday 2 December 1998).

and allowing a child to die, “then it seems defensible to kill the baboon to save the child” (Singer 1992: 732).

The research into non-human sources, despite claims to the contrary, is in the early stages and little is known of the physiological, social, psychological and cultural implications of the procedure. It is likely even if the technique is perfected within the next five years, the consequences of crossing species boundaries will not be known for some time after. Xenotransplantation may be a solution, but it will not be an immediate one, or an easy one.

Summary

Donation rates are static and declining, and the present shortage of organs is cause for concern. There are a multitude of complex factors outwith legal, social, policy and organisational controls i.e. the donor rate is dependent on the number of donors available, and this can be affected by changes such as a decrease in road traffic accidents and how quickly organs can be effectively co-ordinated to the recipient. Medical innovations, such as improved brain imaging, which enables the early detection of haemorrhages in those individuals whose diagnosis is considered hopeless, are no longer ventilated and subsequently unsuitable for donation. Other issues, such as the availability of intensive care unit beds, the lack of funding given to hospitals and a shortage of staff are specific manifestations of the more general chronic shortage of funds available within the National Health Service.

Despite this, discussion has centred on the introduction of other sources or alternative systems. However, this chapter has shown changes in procurement system or source will ultimately be dependent on public acceptability and confidence. Such changes are not likely to happen in the short term. Immediate short-term change and improvement, I would argue, lies in examining the present system. Little is known about why relatives agree or refuse donation and, therefore, one aim of this study is to examine their beliefs, attitudes and experiences. The next chapter offers an overview of previous quantitative and qualitative studies, conducted in Europe and the United States over the last thirty years, enabling a comprehensive overview of the reasons relatives give for their respective decisions.

CHAPTER 3: REVIEW OF RESEARCH INTO DONOR AND NON-DONOR FAMILIES' BELIEFS, ATTITUDES AND EXPERIENCES

Introduction

In Chapter 2, I suggested immediate scope for improving the UK organ procurement system resides in exploring relatives' reasons for agreement or refusal to an organ donation request. Relatives are asked for several reasons, firstly, the 1961 Human Tissue Act dictates their "lack of objection" must be ascertained, secondly, as an act of respect towards the relatives' feelings at a distressing time, and finally they are thought to have known the views of the potential donor regarding organ donation.

Little is known about potential donor relatives' beliefs and experiences, and research tends to throw out a varied and scattered picture. In part, this is a reflection of the aims of the studies, of the population sampled and of the methods used. For example, one limitation of post hoc, qualitative studies investigating donor families, is that conclusions may be one-sided with non-donor accounts neglected (Bartucci and Seller 1986, Fulton *et al.* 1987, Sque and Payne 1996). Comparative research between donor and non-donor families' next-of-kin was conducted in the States (Dejong *et al.* 1998) and the Netherlands (Tymstra *et al.* 1992) providing a more readily accessible, comprehensive view, although applicability to the UK requires verification.

This chapter re-examines the demographic information outlined in Chapter 2, in relation to the effect this has on donation, by grouping the main characteristics of donor and non-donor family groups together. Demographics are useful in delineating intra-group differentials in the population, but do not explain why individuals within groups donate. Research examining the rationale for donation is therefore significant (Bartucci and Seller 1986, Fulton *et al.* 1987, Tymstra *et al.* 1992, Douglass and Daly 1995, Sque and Payne 1996, Dejong *et al.* 1998). Next, attention turns to non-donors and the reasons why they reached their respective decision (BACCN/UKTCA 1995, Tymstra *et al.* 1992, Dejong *et al.* 1998) leading to the discovery of issues pertinent to non-donors, which also pose obstacles for donor families. Themes that repeatedly arise affecting both non/donor families are beliefs about death, brain stem death, and the body (Sanner 1994a, 1994b), suggesting the decision to donate is embedded in a wider network of social and cultural values. An attempt is made to investigate how these values interact with pro- and anti-donation views, and whether familial and health professional dynamics can encourage positive feelings about organ donation (Prottas and Batten 1988, Younger 1990, Gaber *et al.* 1990, Pelletier 1993). The limitations and contributions of both quantitative and

qualitative studies conducted in the UK and elsewhere enables a coherent overview of non-donor and donor family experiences, attitudes and beliefs. In turn, these findings generate and inform the theoretical and empirical investigations in the following chapters of the thesis.

DEMOGRAPHICS OF DONOR AND NON-DONOR FAMILIES

In Chapter 2, I showed certain demographics, such as age, class, education, religion and ethnicity were associated with pro-donation beliefs (B.K.P.A 1994, Gallup 1993, BACCN/UKTCA 1995). For example, consent rates vary by education, socio-economic grouping, age, ethnicity and religion (BKPA 1994, Gallup 1993, BACCN/UKTCA 1995, Burroughs *et al.* 1998).¹⁸

The main weakness regarding demographic data is that it does little in addressing the reasoning behind donor or non-donor families' respective decisions, nor assesses the impact of the specific socio-cultural environment on the decision to donate. Neither does it take into account other factors such as the deceased's characteristics. For example, recent research in Spain suggests families of younger children are more likely to donate (Martínez *et al.* 2001: 407). An examination of the UK BACCN/UKTCA study (1995) into the reasons for relatives' refusal contradicts this. A re-calculation of consent and refusal rates of the deceased's age shows relatives were more likely to refuse when the donor was under 10 years (BACCN/UKTCA 1995: 9). There is a higher rate of consent as the age cohort of the deceased increases; donation was more likely to occur if the donor was aged between 35 – 44 years (BACCN/UKTCA 1995: 9). Such a contradiction in findings draws attention to age of the deceased, in addition to the relatives, as an ambiguous factor in the decision-making processes of relatives. Elsewhere, the BACCN/UKTCA study concluded the respondents' relationship to the patient correlated with a refusal to donate, that is, it was more likely that consent would be obtained if the mother or father of the donor was present, and less likely in a daughter's presence (1995: 7).

Latest quantitative research from Spain also suggests a significant differential relating to sex of the deceased, and a negative expression of donation; family refusal being more likely to occur if the potential donor was female (Martínez *et al.* 2001: 407). This is

¹⁸ In addition Burroughs *et al.* (1998) suggest an inverse relationship between regular attendance at religious services and satisfaction with the decision, although no explanation is forthcoming as to why this is the case.

again unsupported in British studies – as outlined in Chapter 2, an examination of the British Kidney Patient Association annual studies into whether individuals would donate their *own* organs after death, show no significant gender differential, with 82% men and 79% women pro-donation (1997).

In light of the above, a stereotypical UK donor family would appear to be one with white, educated, upper class parents with no religious belief that interferes with organ donation and whose deceased son or daughter was aged between 35 – 44. Why these population characteristics are associated with pro-donation is unclear, although as mentioned in Chapter 2, it may relate to general institutional suspicion and lack of trust in the medical profession, perceived racism in the organ allocation system, lack of knowledge about donation and general linguistic, cultural and religious barriers.

REASONS FOR DONATION

Altruism

So demographic material does not explain heterogeneity intra-group or offer reasons as to why donation did or did not occur. In the early seventies, research began in the United States into families' reasons for agreement to donation (Fulton, Fulton and Simmons 1987). Fulton *et al.* conducted in-depth unstructured interviews with 35 members of 14 donor families. Only families agreeing to donation were interviewed, and as the researchers admit, "[F]amily processes may have been different in families where the donation was refused" (1987: 339). The researchers offer two explanations for donation: altruism and the continuing bodily existence of the deceased relative. Emphasising the importance of "empathy," and awareness of another's need, in most cases the respondent's family thought about the recipient's circumstances, and asked themselves what it would be like if it was their child "lying there, waiting for an organ" (1987: 351). In one case, a woman reported "feeling good" about the decision, satisfied in the knowledge that through donation she helped another (1987: 351):

All I could think about was, "If he's going to die, why not give someone his kidneys?" A doctor from the University came and told us that if you could see the difference in these people's lives after a transplant ... well, it made me feel good.

Batten (1990) demonstrates families reconstruct altruism dependent on the support offered to them during the donation process. Her empirical survey, based on questionnaires mailed to a purposive sample of 396 families of cadaveric donors,

attempted to gauge the respondent concepts of altruism. They were asked how they felt regarding the importance of, “helping others” and, “not to waste organs.” Around 75% said it was important “not to waste organs” and 85% to 90% said they wanted to help others. She found the way families felt they “coped” with the donation experience could be viewed as a “social exchange” for organ donation. One mother hoped, “all parents could be so fortunate. It has helped me to cope with my son’s death and give it some meaning” (Batten 1990: 91). By constructing a discourse around organ donation as the “Gift of Life,” the donor family gain from the knowledge they saved another’s life, enhancing their self-image and gain additional benefits from meaning attached to a sudden and apparently meaningless death.

Body Immortality

Bodily immortality was also a contributory factor in the decision to donate (Fulton *et al.* 1987). In one mother’s words:

I think we generally got approval from most people but kind of like, “Isn’t that nice of her to do this?” I didn’t do it because I thought it was nice to do. I did it because I thought [crying], I guess, something to help him [son]. Perhaps he was alive as far as I was concerned. So his death wasn’t totally a death (Fulton *et al.* 1987: 352).

In this instance, Fulton’s participant explicitly denies the decision was informed by altruistic thoughts, and rejects the expression of social approval from others. This mother had difficulties in coming to terms with her son’s death, and donated so, “his death wasn’t totally a death.” Similarly a father suggested “Well, it’s a funny feeling. In a sense you think they’re still around and yet they’re not. [As long as his kidneys still function] he *isn’t dead* down there (emphasis added 1987: 352).

Though considered seminal, Fulton’s *et al.* work is questionable in its applicability to the present day environment of organ procurement. Then, in the United States, kidney transplantation was the only type of procedure conducted, and donors were transferred to specialist hospitals enabling ventilation. Today, a vast array of organs can be transplanted in most hospitals with intensive care or neurological units. The generalisability of Fulton’s *et al.* findings is also questionable due to the small sample base. Still, all qualitative work into donor (and for that matter non-donor) families cites small numbers for evidence and, in part, is a reflection of the sensitive nature of the fieldwork and logistical problems of tracing willing participants. In order to overcome

such methodological weaknesses, validation can be found in more recent studies. Burroughs *et al.* (1998), have suggested donor families are more likely to have committed prior altruistic acts and are generally associated with an increased level of social volunteerism and civic responsibility. Other research also reiterates the role of altruism and bodily immortality, and locates altruistic tendencies to the deceased, and also suggests families may emotionally gain from donation via the perceived avoidance of a “needless death” (Bartucci and Seller 1985, Douglass and Daly 1995).

Letters

Researchers suggest the need to feel the deceased achieved a certain amount of bodily immortality can be frustrated by the, “lack of long-term information about the recipient’s health as well as some detail about their lives” (Bartucci and Seller 1986: 404, Sque and Payne 1996; Pelletier 1993). They argue that it is crucial for donor families to know the gift was successful. Letters from the recipient or a nurse involved with donation, to the donor family about the recipient’s condition, allows a donor family to reach a sense of “emotional closure” and “confirm that death is real” (Pelletier 1993: 156).

Letters may offer some form of consolation and tangible end to the relatives. In Britain, as far as can be ascertained, the amount of information provided to donor families is limited to age, sex and condition of the recipient (though there are regional variations). It is practice, for example, in some parts of the UK for letters of thanks to be sent to the donor family from the recipient, via the transplant co-ordinator. Little is known about this “gate-keeping” practice, or about donor family responses to the letters. Some researchers report, that regardless of the amount of time passed, receiving a letter was a positive experience. Reasons offered were, “it was gratifying to know that a part of our son lives on in her” “it made me feel the first blessing in this tragedy had just surfaced” and “it was reassuring to know that my son’s death was not a complete loss, that he did some good in dying”¹⁹ (Bartucci and Seller 1986: 402-403). However, other studies suggest the majority of participants were not interested in the recipient, and as one respondent suggests, “I never want to know what they did with them [organs]. It’s not much of a life if you always go round thinking, ‘that’s part of my wife walking there’” (Tymstra *et al.* 1992: 143).

¹⁹ One respondent who had received no letter felt that she could not be “sure that a part of her son was still alive” (Bartucci and Seller 1986: 404).

Donor Decision Making Model – Overcoming Obstacles to Donation

Research into the reasons why donor families donate demonstrates that they do not simply acquiesce to an organ donation request. Rather, in some cases, the decision to donate is not taken until the resolution of certain difficulties is reached. Known as the “Dissonance Model,” Sque and Payne’s research outlines particular behaviours common to donor families, and identifies a continual process of conflict and resolution (Sque and Payne 1996). Conflicts generally had two main forms, firstly, having limited control over the environment and events such as the relative’s death and secondly, fears about the mutilation of the body and accepting the diagnosis of brain stem death. It appears resolution is reached through several strategies: by considering the wishes and/or attributes of the donor, a realisation of the relative’s death and confirming brain stem death (1996: 1363).

This psychological picture of processual factors involved in responses to organ donation should not be thought of as a straight forward series of rational actions with actors processing available information and deciding on a suitable course of action. These decisions take place within a value loaded and highly emotional context. Moreover, it is unlikely all donor families face the same obstacles, some might immediately agree to donation without any discord. The strength of Sque and Payne’s research, however, lies in their emphasis on potential areas of conflict, that some, but not all donor families may need to overcome, and how resolution was reached.

NON-DONOR FAMILIES – REASONS FOR REFUSAL

Non-donor Family Research in the UK

Turning to research into non-donor family beliefs, experiences and attitudes, a quantitative study into the relative refusal rates was conducted by the MORI Health Research Unit (1995) in a survey of British Intensive Care Unit personnel. The BACCN/UKTCA survey was based on self-administered, close-formatted questionnaires, to be completed by the person making the donation request. Results show that refusals can be subsumed into three general areas, not dissimilar to the areas of conflict reported by Sque and Payne’s donor families: i) mutilation of the body, ii) previous wishes of the deceased and iii) familial circumstances are shown below (Table 12).

Table 12 – BACCN/UKTCA Reasons for Refusal

Reason	Figure	Percentage*
THE BODY		
- the person did not want surgery to the body	122	(24%)
- the relative(s) feared that the patient's body would be disfigured	75	(15%)
- the relative(s) felt that the patient had suffered enough	106	(21%)
 DECEASED'S WISHES		
- the patient had stated that in the past that he/she did not wish donation to take place	109	(21%)
 FAMILY CIRCUMSTANCES		
- the relative(s) were divided over the decision	96	(19%)
- the relative(s) were not sure whether the patient would have agreed to organ donation	93	(18%)
- the relative(s) couldn't cope with making a decision	62	(12%)
Total	663	

Base Number (515)

*Due to multiple answers percentages do not add up to 100.

Adapted from: BACCN/UKTCA (1995: 17).

Family Indecision

Leaving aside knowledge of the deceased's wishes, it appears those unsure about their relative's wishes, and organ donation in general, find it easier to refuse than agree (Table 13). Furthermore, an increase in the number of relatives present, correlated with an increasing likelihood of inter-familial conflict about the donation decision (BACCN/UKTCA 1995: 17).²⁰ Tymstra's qualitative study demonstrated a numerical increase in familial presence consolidates relatives' refusal:

I was against it myself and my father-in-law said, 'For what it's worth, I'm against it too. My sister-in-law was there as well, she's a very resolute type, and she was against it too. I was glad that she was there, because you're very vulnerable at a time like that. I am glad that *we* said no, otherwise I might have felt remorseful later on (Tymstra *et al.* 1992: 142).

Carrying a donor card is a decision made on the individual level, but the decision to donate organs can be hindered by the effects of inter-familial interaction; a finding especially pertinent if the individual has not carried a donor card, and their wishes are not known, allowing lee-way for relatives' own beliefs to come into effect. Though it is a group decision, there are powerful normative perceptions about who has the final say, and the extent of influence from the family of origin or the family of procreation (Fulton *et al.* 1987: 345). In the presence of the family of procreation (spouses and elder children for example), the family of origin's input is negated (parents and siblings). On what grounds this exclusion is based is unclear. The source of the tension regarding organ donation is also not defined. Whether it is due to beliefs about organ donation *per se*, or as a result of previous conflict in the family, is unknown. Once the decision is made whom the next-of-kin told, both inside and outside the social network, and their reactions may also be significant. As mentioned previously, though some donor families received a public *kudos* from donating, (Fulton *et al.* 1987) others rejected such social approval, treating donation as a "taboo topic" making an agreement not to let others know about the decision (Tymstra *et al.* 1992: 143).²¹

In sum, more qualitative research is needed into the effect of inter- and intra- familial dynamics, in order to clarify the dynamics during and after the decision, and identify the origins of conflict about organ donation. In some situations, an increase in the number of family members present is the origin of friction regarding the decision, leading to uncertainty about donation, and subsequently solidifying this uncertainty into a negative decision.

Existing Belief Systems

Knowing their relative was pro-donation can make the decision to donate an easier one for the family. It is mostly when the deceased's wishes are unknown, that tension and

²⁰ Sque and Payne (1996: 1363) found in their study of donor families, occasional disagreement about donation in the family, leading to subsequent resentment and conflict.

²¹ Tymstra *et al.* report the case of one family who, "[O]n the way home they made an agreement that no one was to know about the organ donation (i.e. the deceased's children, her brothers and sisters, the rest of the village)." It was not until the researchers had contacted them that donation became known to the rest of the family.

ambiguity regarding organ transplantation have to be resolved. Then, the decision is not straightforward, and the relatives' own belief systems are more likely to come into play. Donor and non-donor families tend to have different views about organ donation and transplantation. Dejong *et al.* conducted 164 structured telephone interviews with donor (n=102) and non-donor families (n=62), 4 to 6 months after the decision, making a comparative analysis less complex.²² Table 13, summarises agreement to the statements given (1998: 16).

Table 13 - Donor and Non-donor Agreement Rates to Statements

Statement	Percentage Of Agreement	
	Donor	Non-donor
Everything was done to save his/her life	91	69
Whether family brought up the subject of donation	24	2
If health professional- whether family felt it was the right time	83	56
Knew that the deceased did not want to donate their organs	1	30
A person cannot recover from brain stem death	80	48
Whether given time to talk about the decision	83	56
It is not important for a person's body to have all of its parts when buried	82	27
Most people benefit from transplants	93	68
The medical staff took time to answer my questions	97	77
The medical staff supported our decision	94	80
The person who made the request did so in a way sensitive to my needs	97	59
I felt comfortable talking with the medical staff about organ donation	92	52
Willingness to accept transplant	93	66

Adapted from Dejong *et al.* (1998: 15).

More donor families than non-donors, would be willing to accept a transplant, 93% compared to 66% respectively (Dejong *et al.* 1998: 15). Donor families were also more likely to agree with the statement that people benefit from transplants (Dejong *et al.* 1998: 18). Non-donor families were more likely to state that it is important that a person has all their parts when buried, and are more likely to believe more could have been done to save

²² Findings of research that only examine donors (Fulton *et al.* 1987, Sque and Payne 1996, Bartucci and Seller 1986) are limited and tend to be one-sided. An examination of only one version of the donation experience, does not make a

the deceased's life. They were also more likely to know donation was against the wishes of the deceased. These findings are consolidated by other research, which shows individuals who thought transplantation was a proven procedure, or if they knew someone who had received an organ, were also more likely to donate (Burroughs *et al.* 1998: 156).

Surgery to the Body/Bodily Integrity

Negative beliefs about organ transplantation are a contributory factor towards refusal. Yet the source of a family's negative belief is not identified. A key to understanding the origins of tension about organ donation may reside in the procedures involved in organ removal. The second group of issues the BACCN/UKTCA (1995) study highlights are concerns related to the body (Table 12). It is interesting that, though the dead body is to be ultimately disposed of, relatives gave the reason, "they did not want surgery to the body" as a rationale for refusal. How surgical procedures to the body would constitute a significant factor in organ donation refusals, when autopsies and dissection have been occurring routinely for the last few centuries, is ambiguous. A representative survey of the Swedish public's reactions to autopsy, organ donation and anatomical dissection, however, demonstrated autopsy was viewed as the most acceptable medical procedure, dissection the least, with organ donation at a mid-way point (Sanner 1994a: 288).

Richardson (1988) discusses how nineteenth century dissection was viewed in popular culture as transgressing the integrity and identity of the body, a sentiment apparently still relevant today. At issue is the acceptable level of interference with the corpse, which is linked to the "symbolism of different uses" (Feinberg 1985: 31). This level is culturally fluid, and dependent on the value of the procedure, an autopsy for example, is more acceptable today than organ donation. Autopsies are not as new a procedure as organ transplantation and have a more mandatory quality attached to them (Sanner, 1994a: 287). The resultant information from the conduction of an autopsy, as opposed to dissection, is immediately beneficial to the family insofar as cause of death is established.

Given the supposed rational and largely secular basis of modern society, the persistence of such reasoning regarding the transgression of identity and integrity, runs contrary to the utilitarian sentiment that what happens to the dead body is irrelevant. However, in the modern era the transmission of cultural beliefs about the dead body takes the form of "the symbolic meaning of showing respect for the individual who once was" (Sanner 1994b:

simultaneous comparison of donor and non-donor families easy to draw.

1148). For example, both donor and non-donor families articulated fears regarding the integrity and identity of the deceased's body, and for some donor families the idea of cutting the dead body produced profound anxiety and stimulated feelings of protection:

I wanted to protect her more, because I mean, she was very vulnerable, wasn't she? For all intents and purposes she was dead, but I did not want her to be cut about. I didn't want her to be injured. You see she was not injured in my eyes, because there was no marks. So anything done after that would be an operation, and I couldn't comprehend that too much, at that particular time. So really that was my reservation, I didn't want her to be hurt (Sque and Payne 1996: 1364).

Sanner suggests, fears about bodily mutilation are related to respect for the deceased, a respect stemming from the living being, and that relatives are confused "...generally not able to imagine a difference between the living and the dead. The dead body was ascribed qualities that only a living individual possesses" (1994b: 1147). Are relatives aware their next-of-kin is dead?

Brain Stem Death

Two issues arise from the BACCN/UKTCA study into the reasons for relatives' refusal – family dynamics and fears about surgery to the body. One factor not identified in this study as an obstacle to organ donation, however, was a diagnosis of brain stem death (BSD), mentioned as a source of dissonance for donor families (Sque and Payne 1996). The BACCN/UKTCA (1995) study gives no indication of confusion regarding BSD from its sample. This finding may stem from the source of the BACCN/UKTCA data, based on health care professionals' interpretation of events, and not that of the relatives.²³ So, although this study offers a comprehensive, account of reasons for refusal, such findings require further verification and examination, in order to establish corroboration with the family themselves.

As discussed in Chapter 2, medically brain stem death is a state similar to decapitation, yet socially death is mapped onto an apparently breathing person. The obvious and taken-for-granted assumption that a dead body, as understood by traditional cardio-pulmonary criteria, is to be equated with the existential death of the person, may

²³ It is likely when relatives refuse, the ICU team would find it increasingly difficult to continue asking for further justification.

occasionally cause doubts about brain stem death.²⁴ With brain stem death, there is not a moment of death as normally associated with the cessation of heartbeat, nor does the status of the dead body fit with everyday taken-for-granted assumptions about how dead bodies appear. Brain stem death has repeatedly arisen in other studies, both quantitative and qualitative, demonstrating donor and non-donor families are affected by BSD, though non-donors are more likely to remain sceptical regarding the diagnosis. Dejong *et al.* (1998) demonstrate only 48% of non-donors agreed with the statement, “a person could not recover from brain stem death” compared to 80% of donors. Equally, qualitative studies demonstrate misunderstandings about brain stem death play a significant role in refusals (Sque and Payne 1996, Tymstra *et al.* 1992, Fulton *et al.* 1987). For example, one woman who donated told researchers, “[My husband’s] mother couldn’t get it through her head - she felt that as long as his heart was beating and he was breathing, he was alive” (Fulton *et al.* 1987: 354). Not being present at the “instant” of death, as defined by cessation of heart beat, only serves to exacerbate the ambiguity of the situation:

For the most part, people said, “Well great.” They thought it was a tremendous thing to do. But I think the majority of them say this not knowing that you give up their organs before their heart has stopped beating. My mother died seven months before he [son] did and I stood at her bedside and felt her pulse until it was completely gone. It’s a different kind of thing when you walk into a room and see the kid is breathing. You know the difference (Fulton *et al.* 1987: 355).

Other donor relatives were more blunt about the decision, “I think the hardest part is the fact that she didn’t die. I had to tell them to ‘pull the plugs,’ I willed her to die.” Another put it as, “[T]here he was, right around the corner, still breathing on a machine and we were signing his life away in here” (Fulton *et al.* 1987: 357). For some relatives, these comments demonstrate a belief they played an active part in ending their loved one’s life, and they continued to have doubts about the diagnosis of death.

Combining a brain stem death diagnosis with the shock and unexpected nature of its causation, either through an internal or external trauma to the head only exacerbates the situation further. Again, if a sufficient amount of time is not allowed, enabling relatives to come to terms with the suddenness of their loss, can also lead to refusal:

²⁴ In Sanner’s study (1994a) 22% of the undecided about organ donation stated this was due to a fear of not actually being dead. However, her study pertains to the Swedish population and it is questionable to what extent it is applicable to the UK

They asked me whether I had ever heard of organ donation. I refused. It was such a disagreeable way of asking for permission; it was a strange, unreal situation. Maybe if they had given me a quarter of an hour, or half an hour in between, I would have said yes' (Tymstra et al. 1992: 142).

If families are not prepared by health professionals for the imminence of death, and have not reached an understanding of the diagnosis, they are more likely to react with anger, shouting and extreme distress, making the request and gaining consent problematic (Martínez 2001). Donor families have also emphasised the effect of shock, and lack of anticipatory grief, which can hinder an understanding of information provided by health professionals (Douglass and Daly 1995: 97). Such reactions to the diagnosis of death are likely to be a contributory factor in refusal.²⁵

Thus, most studies show relatives' understanding of BSD, and their views on the body can pose obstacles to donation. A numerical increase in the number of families present arguably leads to an increase in the amount of uncertainty. In other words, the more individuals involved, the more likely there is an increased scope for differing beliefs and understandings about death, the status of the dead body and organ donation. Interactions between these belief systems and health professionals are identified as factors affecting the decision to donate or not. A breakdown of communication within the boundaries of the group, and across its perimeters, involving different value and knowledge systems can lead to potential conflict. As evidence, donor and non-donor relatives have different views on the level of care provided by health professionals (Dejong *et al.* 1998). As can be seen from Table 13, non-donors were less likely to feel comfortable talking to health professionals, less likely to state the request was sensitively made, and that staff took time to answer their questions. Dejong *et al.* conclude non-donors were more likely to pronounce the hospital did not offer them enough support, and "a bond of trust between the family and health care providers [was] never established, leading the family not to donate" (Dejong *et al.* 1998: 21).

The Role of Health Professionals

In the absence of pro-donation views, and in the presence of uncertainty in the family group, the role of clinical staff becomes pivotal. Medical professionals have a key role in organ procurement, as a source of providing information and support, due to their

environment.

²⁵ This is, of course, not always the situation. One participant in Sque and Payne's study felt that the confirmation of brain stem death was "almost academic" (Sque and Payne 1996: 1362).

position as first point of contact for the relatives of a critically ill patient. It is undeniable that those requesting organs are in an onerous position. They have to come to terms with the fact that their role has changed from one that directly saves the life of a patient, to one that requests organs for an anonymous other. Moreover, they are expected to take on the latter duty with a high level of sensitivity and tact. Some families recognise and sympathise with the position health professionals are in (Sque and Payne 1996: 1363). However, it is likely in such distressing circumstances, the potential for a break down in communication is significantly increased (Tymstra 1992: 143 and see Fulton *et al.* 1987).

Health Professional Attitudes towards the Body

One area, where health professionals require a high level of tact and sensitivity, is the treatment of the dead body. The saliency of the relatives' attitudes towards the deceased's body is evident in cases where health professionals are perceived to be transgressing the integrity and identity of deceased's body. Relatives have accused health professionals of treating the deceased as a "used car," taking body parts they did not have permission for:

The recovery team was full of pretence and false concern, trying to get me to sign over my mother as if she were a used car to be parted out with my permission.

They went in and removed bones I had not agreed to donate and in doing so severed arteries. My son could not be embalmed and I could not have him laid out. His four-year-old daughter was not able to see him one last time (Bartucci and Seller 1986: 403).

Apparently, there are significant differences in how clinical staff and relatives view the status of the deceased's body, raising interesting questions about how a dead body is socially constructed by different groups. For some relatives, the dead body is the site where they express their feelings of love and loss, and remains to be a symbol of the person that once was (Prior 1989). Despite the end of physical life, feelings towards the deceased persist. For health professionals, on the other hand, the body may simply be a resource for organs. They have not experienced the same degree of emotional attachment that stems from having a kinship connection or close relationship with the deceased. Such a dichotomy may therefore create tension at a crucial juncture – the organ donation request. Yet the origin of such belief systems is unclear, their pervasiveness unknown, and the dichotomies for demarcation ambiguous, requiring further sociological discussion.

Health Professional Attitudes to Organ Donation

Although clinical staff can inadvertently transgress cultural belief systems regarding the dead body by treating the deceased as a resource for organs, the dichotomy between lay and medical social worlds should not be over-emphasised. Studies have shown health professionals can be subject to the same doubts regarding BSD as the families themselves. The attitudes and belief systems of health professionals are clearly important elements in the procurement process. However, nurses and physicians can be hesitant in approaching families, due to similar concerns relating to interference with the corpse and difficulties accepting brain stem death (Bidigare and Oermann 1991: 21). Caring for a brain dead individual involves treating them as any other living patient:

Machines are not turned off, nor are tubes and lines removed ... staff must follow rigorous protocols monitoring "life" functions such as blood pressure, heart rate, and temperature ... Should this dead patient have a cardiac arrest, specific instructions are given to perform cardiopulmonary resuscitation. Finally, the dead donor is sent to the operating room instead of the morgue" (Younger 1990: 4).

Clinical and conceptual confusion regarding the status of brain dead individuals as dead,²⁶ and resistance and discomfort discussing death and organ donation with the families, has been reported (Younger 1990: 2). Verification is found in recent, larger surveys of over 1000 non-physician professionals, consisting of nurses and other health care professionals working in ICU, operating and emergency rooms (Gaber, Hall, Phillips, Trolley and Britt 1990). Results demonstrate, although over 90% of respondents had no moral objections to donation or transplantation, only 45% indicated willingness to donate their own organs and 50% to donate their relatives; this is a substantially lower level of support for organ donation when compared with public surveys.²⁷ Gaber *et al.* (1990) suggest:

²⁶ For example, only 63% of clinical staff defined the "irreversible loss of all brain function as the medical criterion for declaring a patient brain dead" (Younger 1990: 2).

²⁷ Studies quoted in the King's Fund Institute Report (1994: 40) suggest approximately 70% of the British population have a positive attitude towards donation.

... when asked their personal opinion, only 64.5% acknowledged that brain stem death constitutes actual death ... [and a] significant percentage expressed personal concerns regarding participation in organ donation and approaching families to request such a donation. Thirty five per cent stated that the request for donation places the bereaved family under unfair strain. Forty-three per cent felt that their solicitation of organs could be offensive to the family of the donor ... (1990: 314).

Health professionals with prior experience in approaching families for donation and caring for an organ donor, were more likely to indicate willingness to approach donor families, leading to the conclusion that experience, as well as education, is important in the negotiation of organs (Gaber *et al.* 1990). Similar studies into nurses' knowledge and attitudes towards organ procurement find the same results (Bidigare and Oermann 1991). Although nurses were supportive of organ transplantation, they were uncomfortable with some aspects of the process, especially approaching relatives. Those nurses demonstrating higher knowledge scores about the donation process were more likely to be positive about donation in general, and comfortable in approaching relatives.²⁸

Evidence from such studies demonstrates that professional attitudes towards brain stem death and approaching for consent remain the "weak area in the procurement process that must be remedied" (Gaber *et al.* 1990: 314).²⁹ Failure to approach donor families is linked to a fear of "intruding or even worsening the families' grief" (Willis and Skelley [1992] quoted in Pelletier 1993: 155) and arguably to a genuine concern about encroaching on the families' grief, and indecision about how best to approach them. If, some health professionals are emotionally and conceptually confused about BSD, then there may be difficulty in effectively communicating understanding to grieving family members.³⁰

²⁸ Nurses were also identified by the families in the Pelletier (1993) study, as the health care professionals most likely to meet their need for emotional support and show empathy and sensitivity to the care of their relative.

²⁹ A description reaffirmed by Protas ([1987] as quoted in Pelletier 1993: 155) who also stated that health professionals are the "weakest link" in the donation process.

³⁰ Significantly, such findings are again at odds with the results of the BACCN/UKTCA (1995) study. The reasons given for the 12% non-approachment rate (apart from relatives stating that they did not want organ donation to take place before they were asked) were usually medical ones. At no point is there an indication health professionals were unwilling to approach the relatives due to concerns about the intrusion of grief or indecision about how best to ask.

The Stability of Family Decisions to Consent and Refuse

The assumption that non-donor families are more likely to regret their decision, as they have decided not to alleviate another's suffering, appears initially unfounded. A recent quantitative study based on a purposive telephone survey, examining donor and non-donor families' views post-donation, found 21% were dissatisfied with their decision. Statements of dissatisfaction were equally split between donors who would not donate again, and non-donors who would donate (Burroughs *et al.* 1998). Sources of regret for the donor families appear to stem from concerns about the transplant procedures:

They asked for his organs. We didn't have to say yes at once and they wouldn't have blamed us at all if we had said no, they showed such understanding. They didn't try to force us or anything. But I've always felt very sorry that we said yes,' (at which point she left the room in tears). Later she said, 'I can't bear the idea that they still cut up his body, while he was so proud of it (Tymstra *et al.* 1992: 143).

Of those respondents who refused, non-donor families stated they had no regrets and had made the correct decision, "our son informed us clearly that he would never want to donate his organs and we respected that. We've never had any regrets" (Tymstra *et al.* 1992: 143).

SUMMARY

The contribution of previous findings enables an identification of several inter-related areas: understanding of brain stem death, acceptance of procedures conducted on the dead body, family dynamics, support from health professionals and beliefs about the value of organ donation. It is how these areas intersect, and contradict each other, that will become the focus of this study.

There are limitations to the findings previously discussed. It was suggested, for example, donor families donate because of reasons relating to altruism and body immortality. The organ procurement system is based on, and promoted through, the social value of altruism. However, an altruistic explanation is circular: donor families donate because they are said to be altruistic, donor families are said to be altruistic because they donate, leading into a theoretical cul-de-sac. Additionally, researchers neglect to offer a definition of what is meant when employing the term "altruism," offering on the one hand "empathy with others," and on the other, an "emotional reward to help cope with death." Common sense definitions of altruism, regard it as an unreciprocated act, as the adage "giving something for nothing" in everyday discourse attests to. Moreover, Fulton *et*

al.'s sample showed some respondents explicitly denying the donation act was informed by altruistic tendencies. Neither is it clear in this study, whether or not the deceased carried a donor card and what impact this had, if any, on the donation to donate. It would appear that the role of altruism, as a rationale for donation, requires further investigation. For example, it would be helpful to define the concept prior to operationalisation in research enabling an evaluation of its applicability. Such a definition shall be offered in Chapter 4, when the wider sociological significance of altruism and gifting is theoretically investigated.

Equally, in what way can an explanation of bodily immortality be explained as a reason for transplantation? Is this symptomatic of a wider modern day denial of death? What is the relationship between the dead body, the person and its parts? Initially, such a finding appears to suggest that, somehow, vestiges of the person are carried within the organs. How widespread is such a conceptualisation? And what are the origins of such a belief? Moreover, such a perception paradoxically leads to fears about the organ removal procedures, raising concerns about the repercussions for bodily identity and integrity. Is this "respect for the body," as Sanner suggests, due to relatives' inability to tell the difference between a living and dead person? (1994a, 1994b). Both relatives and, indeed health professionals, were cited in numerous studies as suffering from varying degrees of confusion about BSD. Nonetheless, this seems a rather perfunctory explanation. The emphasis on bodily respect has been sourced to the nineteenth century, and as such has a historical basis (Richardson 1988). Beliefs about respecting the deceased's body did not arise with a conceptualisation of death as BSD

The roles of cultural ideologies regarding the status of the body and its parts, and their relationship to personhood and death, are murky. Both are ambiguous factors in organ donation worthy of further consideration, and a full discussion will be offered in Chapter 5, when attention turns to the social construction of death, the body and its parts. This chapter has demonstrated organ donation is not an individual act, but a group decision, grounded in wider socio-cultural values associated with gifting and the body. For example, donor and non-donor families appear to face the same obstacles to donation, especially regarding BSD and fears about integrity of the dead body, a routine finding in most of the discussed studies. This can be exacerbated by several factors: the suddenness of the death, the families' subsequent reaction, the appearance of the dead body, and not having a moment of death as normally associated with the cessation of cardiac arrest.

Nonetheless, donor families are more likely to have such fears assuaged by significant others, such as family members, and by health professionals. Donor families, are more likely to have positive beliefs regarding the value of organ donation, and more likely to have known the deceased carried a donor card. In contrast, non-donor families appear less likely to report familial and hospital support, the deceased is less likely to have carried a donor card, and the families own negative beliefs about donation can enter the decision. Then, non-donor families refuse, not purely because they knew their relative was against it, but because they have a different belief system about the benefits of organ transplantation. Their cultural and social beliefs, about not mutilating the body and doubts about brain stem death, are unlikely to be assuaged or overcome if organ donation is not held to have a positive purpose either by themselves, other family members or the donor.

What is clear from the above discussion is that the decision to donate is tied to the socio-cultural context; it doesn't take "place in isolation within the individual mind but is motivated by *values that are culturally embedded*"(Sque and Payne 1996: 1369, emphasis added). In the following two chapters, a theoretical attempt to gain an in-depth understanding of these cultural values of gifting and of the body, and how they inter-relate with organ donation and transplantation, shall be offered.

CHAPTER 4: ORGAN DONATION – ALTRUISM IN ACTION?

Everyone will agree that organ donation is one of the finest gestures of fraternity and love of which man [sic.] is capable.

Organ Transplantation, First report: Ethical and Socio-cultural Problems raised by Organ Transplantation (Council of Europe, Strasbourg [1987] quoted in Evans 1989).

Introduction

As shown in the previous chapter, researchers analysing why families choose to donate suggest they do so, because of reasons pertaining to “altruism,” and this is informed by both qualitative and quantitative studies (Fulton *et al.* 1987, Batten 1990). The UK organ donation system is based on principles of anonymity and voluntariness, with the potential for reciprocity denied, thereby invoking the term altruism to describe both system and an individual’s behaviour within it. However, the main contention made in this chapter is that it is highly questionable to extrapolate individual motivation from the ethos of the collective way blood and organs are procured in the UK. Although organs are donated, this is not a sufficient premise to argue all families who decide to donate are altruistic. Therefore, it is proposed in this chapter, researchers who take it for granted that donation stems from purely altruistic reasons have neglected the families of some organ donors, who donate from other reasons.

In general, “altruism” as a concept and a rationale for gifting tends to be rejected within the social sciences, in favour of the term “exchange.” Due to the prevalence of market relationships in most modern Capitalist societies, and the ubiquity of “political economy” in social science theorising, the terms, “exchange” and “reciprocity” are pervasive. On the whole, there are two types of exchange subsumed under the ideology of the political economy, specifically *market* and *social* exchange. Due to the perceived failure of the present voluntary altruistic system of organ donation, economists have argued market exchange principles should be used in order to increase the supply of organs. Offering financial incentives to the relatives, it is argued, would induce more individuals to donate as they receive some monetary return. Titmuss, however, argues that cases where market principles have been used, to procure blood for example, have had immoral and undesirable practical repercussions (Titmuss 1970). That is, paid blood donation was a

danger to both donor and recipient and, in the long term, created shortages in supply.

By drawing on the work of Marcel Mauss, Titmuss argues that blood donation, though an example of “exchange” behaviour, is not that of the market category, rather it can be described as “social” or “gift” exchange. Mauss viewed gifting, and individuals who gift, as purely self-interested actions and actors within his theory of the tripartite obligation of gifting; the obligation to give; the obligation to receive; and the obligation to reciprocate. These actions, he argues, are the basis of gifting exchange in archaic societies. Authors such as Sque and Payne (1994) and Fox and Swazey (1989), also reject altruistic explanations, suggesting that the behaviour of families who decide to donate organs, can be located within the idea of “exchange.” Again, the gift exchange, suggests that “the freedom to give or receive an organ is neither absolute or random. This freedom is mediated and governed by the norms of gift exchange” (1978: 5: 1994: 48). Here, it will be argued, that the obligatory aspect of social exchange, as applied to both blood and organ donation, is questionable and its source and nature requiring further investigation.

Ultimately, any over-arching explanation for all donating behaviour leads researchers up theoretical cul-de-sacs. There is no mono-causal motivation or explanation for donation – a society is made up of individuals that *ipso facto* have different and varying reasons for their actions. In sum, the main problem with all these explanations: altruism, social and market exchange is that they give “a highly decontextualised model of human action, minimising the normative bases and different forms of “giving” (Machado 1998: 59). In other words, there are different gifts, different forms of “giving” and different reasons as to why the gift is offered. The aim of this chapter, is to re-insert and analyse the different forms of gifting that specifically involve the body, and are subsumed under voluntary, unreciprocated systems of donation:

- 1) In the UK, blood donation, is given under an ethos of no gain to the donor and arguably rests on the same system of “altruism” as cadaveric organ donation (though it is a replenishable bodily material donated by a living donor). Research by Titmuss (1970) may therefore be informative as regards why people give parts of the body.
- 2) The family’s decision to gift organs after the donor has died. Known as “cadaveric donation” the relatives are considered “proxy donors.” Like blood donation, organ procurement is based on a voluntary system, based on the principles of anonymity, and the potential for reciprocity is blocked.
- 3) “Living donation” when a related individual donates one of their paired organs whilst

alive to a recipient, usually a parent, child or sibling. This is not anonymous; it is potentially obligated and reciprocable.

Though the focus is on cadaveric donation, lessons may be learned and propositions deduced from contrasting this with blood and living donation. What is apparent, is that actors negotiate their behaviour within a specific socio-cultural environment. The immediate social environment of cadaveric organ donation cannot be ignored, and the relevance of inter- and intra- familial dynamics, of interactions with health professionals, of the suddenness of death and doubts about the diagnosis of brain death are, of course, important. Such findings have obvious input into policies regarding organ donation and transplantation, yet one can also learn more about the nature of society, relationships and bodies through such an examination. It is what we can learn from this phenomenon, which will be the focal points over the next two chapters. Unlike previous chapters, the discussion turns to what sociologists can learn from organ donation and transplantation—revolving around the two main tenets of *gifting* and *the body*. That is, the families' decision making takes place against a backdrop of varying cultural and social values regarding the worth of gifting and the gift – of how important the donation and the body are. Their decisions are informed by the importance they place on differing (and occasionally conflicting) cultural values. The gift of the body may be the most sacred item that any person can offer to another. Alternatively, this sacredness can also be the reason why it is not offered.

THEORIES OF GIFTING

Simmel (1958) once wrote that the gift in all its forms demonstrates the “greatest wealth of sociological constellations, because the attitude and position of the giver and of the recipient are most diversely combined in it in all their individual nuances” (quoted in Berking 1999: 10). Given this wealth of information that studying gifting and social actors can offer the sociologist, the lack of sociological theorising is surprising. When it does occur, it tends to take the form of viewing gifting as social or market exchange behaviour (cf. Shrift 1997). Partly, as Cheal (1988) argues, this is due to the influence of an inter-disciplinary approach known as the “political economy” paradigm. Such an approach takes the view that gift-giving *was* a ubiquitous economic transaction in pre-capitalist societies.³¹ The onslaught of a market exchange system, however, eroded gift-

³¹ Zelizer (1979), for example, demonstrates that in nineteenth century America, bereavement support moved from a gift-type mutual aid to an impersonal market system of insurance companies. Thus, she states that transactions with other families and neighbours were replaced with organisational transactions and the management of death therefore became

giving and capitalist relationships began replacing morals with markets (Polanyi 1957).

The Economist Explanation

In modern twentieth century society it is easily assumed that gifts are relatively unimportant. Arguably, the widespread existence and success of a capitalist ethos in meeting individual needs is testament to this. By definition, capitalist exchange involves market transactions, where commodities are transferred within a monetary nexus. The relationships are usually temporary, carried out between two distant individuals, who may then leave the transaction unhindered by further debt. Due to the ubiquitous nature of market relations, and exchanges for mutual gain in modern society, cynicism is often directed at gift-giving purely motivated by “other” centred orientations without the motivation of advantage.

In the thinking of some economists, individuals act only with the expectation of reward, and an “economics of society” seems to be in tune with current political sensibilities. “Rational-choice” theory, with its assumptions of egoistic, rational calculating actors is currently enjoying a revival.³² Since the 1980’s, economists have become increasingly ambitious and strident in their claims that economics can explain a host of social phenomena. Models of maximising behaviour are widely used in economics, and rational choice analysis can be understood as extending that approach to other areas of human life. Becker states his view that:

The economic approach is applicable to all human behaviour, be it behaviour involving money prices or imputed shadow prices, repeated or infrequent decisions, large or minor decisions, emotional or mechanical ends, rich or poor persons, men or women, adults or children, brilliant or stupid persons, businessmen or politicians, teachers or students (1976: 8).

In the economist’s view, actors are assumed to be rational, self-interested utilitarians, who can be randomly picked from their groups to be studied. It really makes no difference who they are – they are easily interchangeable, and all work under the same principle of reward. Such comments are suggestive of a reductionist, individualistic view of human motivation and may therefore lack any significant insight into the nature of social

formalised and rationalised. Beliefs about life and death also altered. According to Zelizer it broke “a powerful normative pattern: the division between the marketable and the non-marketable, or the sacred and the profane” (1979: 43).

³² Perhaps it is no coincidence that the popularity of proposals to sell organs began to rise in the early eighties, a period of Thatcherite neo-liberal economics.

interaction and behaviour. However, the economists draw on the central ethos of modern Capitalist society, the cash nexus, and the widespread ideology that there can never be “something for nothing,” which has arguably been the economic basis of modern societies. The economic explanation of market exchange, and a solution based on reward, might be valuable in explaining and solving the problem of the organ shortage.

Social Exchange Theory

Mauss, in a similar fashion, showed that such an exchange paradigm was equally successful in pre-Capitalist societies, albeit through a differing mechanism. Gift-giving served as a form of economic exchange, and the tripartite obligation to give, to receive and to reciprocate, created and stabilised social relationships, essentially maintaining social cohesion through the economic distribution of goods and services. In the archaic societies Mauss studied, instead of both parties leaving the transaction as free agents, as in market exchange, social exchange leads to the creation or maintenance of social bonds through a system of indebted gifting. Hence, in the functionalist writing of Mauss, what is wrong with a gift given without return is “the donor’s intention to be exempt from return gifts coming from the recipient. Refusing requital puts the act of giving outside mutual ties ... A gift that does nothing to enhance solidarity is a contradiction” (Mauss, [1950], 1990: vii). Some theorists have found the paradigm of gift exchange applicable to theorising about organ donation, as it stresses the role of obligation and reciprocity, and emphasises the importance of indebted social relationships.

Altruism

Gouldner (1973) links the norm of reciprocity to an “everyday morality” – that is, due to the pervasiveness of market relations and mutual exchange, reciprocity is a ubiquitous social interaction. However, he also suggests that there is a norm of “beneficence that encompasses more specific orientations such as altruism, when individuals give, “something for nothing” (Gouldner 1973: 266). Unlike the norm of reciprocity, the norm of beneficence is considered a “higher morality” (Gouldner 1973: 271) and contains with it a “value element” to the action.

Altruism comes from the Latin word, *alter* meaning *other*. The social significance and meaning of altruism is generally an area that sociologists neglect, though it is a favoured topic for philosophical exploration. Indeed Paul, Miller and Paul (1993) argue that, the central issue of moral philosophy is trying to find a balance between a regard for the self and a regard for others. In the “Leviathan,” Hobbes questioned whether such “other”

orientated sentiments existed, arguing that showing concern for others is only a means of avoiding a lonely, short life. Hobbes, convinced that all individuals are self-seeking and egotistical, argued that apparently selfless acts are in fact merely disguised forms of self-seeking behaviour (quoted in Page 1996: 4). Auguste Comte, on the other hand, used the word “altruism” to describe “a devotion to the interests of others as an action-guiding principle.” Comte thus viewed the “chief problem of human life [as] the subordination of egoism to altruism” (quoted in Paul *et al.* 1993: ix). There is a necessary and important distinction between altruism, self-interest and selfishness. Frequently, what is lost in any discussion of altruism is the distinction between self-interest and selfishness. In part, this is due to the way the opposition of altruism to egoism is constructed. Egoism often serves as an umbrella term for both selfishness and self-interest. Worthy of note, is that individuals can often pursue their own self-interest, without necessarily being selfish. Individuals who are selfish, by contrast, will necessarily be pursuing their own self-interest, often to the detriment of others.

Without wishing to build false dichotomies, it should be apparent that there is a fundamental difference, between whether gifting can be defined as a two way reciprocal exchange, or alternatively, whether gifting can be described as a purely one way occurrence. On the one hand, economists and anthropologists raise the question of whether gifting can ever be unreciprocated, and whether it is ever conducted for purely “other” motivated reasons. Essentially, a good is given so that some gain or return might be forthcoming to the giver. In a similar manner, functionalist writing on gift-giving views it also as a form of exchange – the giver gives, the gift is received and then reciprocated in turn, thereby completing a circle of goods. This, as was argued by Mauss, was the economic basis of traditional societies. A gift without the expectation of return, that is a gift given altruistically, subverts this process. Yet, although reciprocity may be a key feature in modern society, there are also actions that are voluntary, without want of return, and with the need of others in mind, actions that we like to call altruistic. If one accepted this is the case, and that the phenomenon of altruism did exist, in what way could it be described, and therefore investigated? Obviously, the voluntariness and desire to help others in need would be central principles, as would the lack of any apparent gain. The action would also be beyond the call of duty and obligation, as this implies some form of normative coercion. It would be likely that the act does not harm anyone, and that conducting an altruistic action does not contain an element of self-sacrifice, at least not out of proportion with the gain to the other.

One difficulty in studying the motivational basis of any action is whether, and how, we can determine the fundamental causes. This is especially the case when attempts are made to observe whether altruism is involved. Because of widespread doubt regarding whether an action can be called altruistic, the potential for reward has to be eliminated. With the spectre of return, cynicism is directed towards the supposedly altruistic act, which can be disputed on the grounds that it serves the self-interest of the individual. One way of getting round the problem of ascertaining motivation, is to employ the natural sciences conceptualisation of altruistic action. Completely ignoring the motivational basis of altruism, biologists focus mainly on the effects:

Rightly or wrongly, zoologists do not concern themselves with such questions of subjective motive. We do not deny that animals have feelings and intentions, but we make more progress in understanding ... effects and do not speculate about the animal's intentions. An altruistic act is one that has the effect of increasing the chance of survival (some would prefer to say 'reproductive success') of another organism at the expense of the altruists (quoted in Page 1996: 2).

Obviously, as individuals we do not purely practise altruism to increase "reproductive success." However, due to the apparent difficulty in determining whether or not acts can ever be purely motivated by altruism, some commentators, following the natural sciences perspective, have proposed non-motivational conceptions of social altruism, which focus specifically on the individual's actions. Such a behavioural approach thereby:

... solves the endless, and fruitless, debate as to whether such a thing as true altruism exists. For example, it may be true that there will never be a total absence of all possible rewards, including such internal ones as the relief of guilt, pleasure for having lived up to an internal standard, reduction in a sense of justice, or termination of a sympathetic feeling of pain for another ... let us note that there is a class of behaviours which are carried out in the absence of immediate reward and sometimes at some cost. Most people consider such behaviour by their peers a virtue. It is useful to have a word for such behaviour and "altruism" is the one designated (Rushton [1980] quoted in Page 1996 9-10).

Page, however, contends that such a behavioural approach is likely to lead to a false assessment of apparently altruistic actions (1996: 6). The example he gives, is that of a young man coming to the assistance of an elderly woman who has dropped her shopping,

only in order to steal her purse. In Page's view, motives are an essential part of analysing altruism. Yet, Page fails to recognise his example could also be defined behaviourally; the stealing of the lady's purse shows the primary motive. The act, considered in its entirety, is not altruistic. A further difficulty is, it is unlikely that people act from solely one motive. For example, Schmitz (quoted in Paul, Miller and Paul 1993: 52) suggests that altruistic action can only be called such when it is motivated purely by a desire to help others. Yet he also adds, "people can act from mixed motives" (quoted in Paul, Miller and Paul 1993: 52). The example he gives is Robin Hood, who "while helping the poor, can also look good and hurt the rich." Therefore, his actions are simultaneously self-serving, altruistic and vicious.

It would, however, be unwise and premature to examine only behavioural aspects of action because establishing motive is difficult. Observing behaviour is useful in understanding why actors undertook their actions, but may not offer a deeper understanding of how they themselves define them. For example, an observer could argue Robin Hood was purely self-interested, only giving money to the poor to appear beneficent, whereas according to Robin's interpretation of his actions, he was acting altruistically. Ignoring accounts offered by an individual because they are deemed an untrustworthy agent is, at best paternalistic, and at worst, arrogant. The difference between observing animal and human behaviour (and indeed the difference between animals and humans) is that humans can communicate what they considered were the important mechanisms underlying their actions and this, of course, is a valuable source of information in grasping what the motivation for action is. Empirically speaking, although it is difficult to know the reasons why people act *per se*, researchers can observe behaviour while listening to, and interpreting the respondent's own reasons, for their action.

ALTRUISM IN ACTION? BLOOD DONATION

Despite such difficulties regarding the motivation of individuals, Titmuss's (1970) seminal comparative study of blood donation, offers valuable insights into why people give. He examined the motives of paid American blood donors and British voluntary ones. In the case of the latter, Titmuss pondered the question that is applicable in the case of both organ and blood donation - "Why give to a stranger"? Table 14, is a breakdown of the answers that 3325 British donors gave, as the reasons for why they donated blood (1970: 309).

Table 14 - Motives of Blood Donors

1. Altruism “a desire to help people”	26.4%
2. General Appeal	18.0%
3. Personal Appeal (by individuals known to them)	13.2%
4. Reciprocity (to repay a transfusion or in case of need)	9.8%
5. War Effort (those who first gave blood during the war)	6.7%
6. Awareness of Need for Blood	6.4%
7. Defence Services since 1945	5.0%
8. Miscellaneous	5.0%
9. Duty (religious or societal)	3.5%
10. To Obtain Some Benefit (such as finding out what blood group they are)	1.8%
11. Gratitude for Good Health	1.4%
12. Rare Blood Group	1.1%
13. Replacement	0.8%
Total	100%

Though there are methodological problems with Titmuss’s survey (for example, the wording and format of the questions about motives led to confused, and sometimes, uninterpretable answers) the most common motives can still be inferred from the above results:

1) A response to public and individual appeals for donation	31.2%
2) A generalised desire to benefit others	26.4%
3) To repay a transfusion or in case of need	9.8%

As is discernible, there is no one motive to donate blood. A third of individuals donated as a result of public campaigns, or because someone had asked them to. Approximately, a quarter of the respondents donated blood as a gesture to help others in need: “a generalised desire to benefit others.” Finally, nearly 10% of Titmuss’s voluntary donors gave blood as a result of having received a donation themselves or in case of future need. Therefore, some individuals donated blood because they were asked, others because they wanted to help those in need, and finally, a small group because of what can be termed a form of “exchange,” albeit not financial, but in case of past or future need. It is probable that, just as different individuals have differing reasons for donation, it is likely that the same individual might also be acting with several motives in mind, therefore these categories should not be treated as mutually exclusive. For example, a person may donate blood

because they received a transfusion and in response to appeals.

Titmuss - Altruism and the Consolidation of Social Bonds

Titmuss concluded, the voluntary exchange of blood is therefore a social and moral good, that in effect, an exercise in altruism which strengthens community feeling, as the voluntary donation of blood institutionalises altruism and encourages individuals to care for unknown others. Oakley and Ashton (1997: 8) suggest Titmuss believed the voluntary donation of blood was an example of giving, “in its purest form, because people give without the expectation that they will necessarily be given to in return.” Titmuss argued that, “... there is no formal contract, no legal bond, no situation of power, domination, constraint, or compulsion, no sense of shame or guilt, no gratitude imperative, no need for penitence, no money and no explicit guarantee of or wish for a reward or a return gift. They are acts of free will; of the exercise of choice; of conscience without shame” (1970: 89). Yet Titmuss also suggested:

... that there must be some sense of *obligation*, *approval* and *interest*; some awareness of need and of the purposes of the gift. What was seen by these donors as a good for strangers in the here-and-now could be (they said or implied) a good for themselves - indeterminately one day. But it was not a good which they positively desired for themselves either immediately or ultimately” (1970: 239, emphasis added).

On the one hand, Titmuss readily admits, as his results show, altruism plays a part as a motive for blood donors. His findings reiterate the fact that, because there is no compulsion to donate, it is a voluntary choice and there is no explicit guarantee of reward or return gift. Donating blood can be considered a supererogatory act - almost above and beyond the call of duty. The lack of desire for a return gift is probable, given for the donor to become donee implies some misfortune befalls them. Yet why does Titmuss also want to suggest there is an obligation to give? Why does an apparent contradiction between obligation and voluntariness, altruism and self-interest arise in Titmuss's work?

Titmuss argued that the way in which society organises itself could encourage or discourage altruism. As individuals, we are not born altruistic or selfish - we learn these values, just as we learn any other, from surrounding social institutions that consider altruism to be socially valuable. In that sense, altruism is not entirely “voluntary.” Yet this is not to be confused with the “involuntariness” of gifting the anthropologist Marcel Mauss

offers. Mauss, was certainly fascinated with exchange and contracts that, in theory are voluntary, but in practice, are given for reasons of self-interest and reciprocated obligatorily. “In any society it is in the nature of the gift in the end to bring its own reward” quotes Titmuss in Maussian fashion (1970: 72).

While Titmuss accepts altruism plays a part in the donation of blood, Mauss rejected the motivation of otherness out-right, arguing that a gift given without reward, subverts the tripartite obligation to give, to receive and to reciprocate.³³ Titmuss failed to notice in Mauss’s work, that altruistic gifts do not maintain the exchange relationship. Moreover, Titmuss’s argument that blood donation is an exercise in social bonding, and therefore contributes to the overall cohesion of society, is exaggerated. Estimates from the National Blood Transfusion Service suggest in 1999, less than 5% of the population donated blood on a regular basis. Though the donation of blood is institutionalised in an altruistic manner, it is unlikely this will lead to widespread social cohesion, given the small number of people donating.³⁴

Titmuss’s work does demonstrate, that individuals may participate in a system based on altruism and voluntariness, but their reasons for doing so vary. It is undeniable some individuals’ motivation coincides with the principles of the altruistic system, yet there are also discernible elements of social exchange. For example, some individuals suggested they donated blood because they had received a transfusion in the past, or in case of future need. Though the obligatory emphasis in Mauss’s argument may not be strictly transferable to blood donation, self-interest and reciprocation are relevant. The question is, if this is the case for blood donation, can it be applied to organ donation? Before addressing this question, a closer examination is given to the nature of reciprocity. If reciprocity is an integral part of blood donation, what is its form and nature? Can, for example, a financial recompense encourage individuals to donate blood by appeals to self-interest?

FINANCIAL INCENTIVES AND BLOOD DONATION

Overall, the applicability of Titmuss’s arguments regarding the cohesive functions of blood donation may be questionable. However, he offered three damning criticisms of a commercial blood transfusion system, first, it was a danger to the donor, second, a danger to the recipient and finally, a private market, in the long run, creates greater shortages

³³ To some extent the differences between Titmuss and Mauss lies in the differing social contexts that they analyse. That is, Titmuss work pertains to contemporary Britain whereas Mauss examines pre-Capitalist societies.

³⁴ Asides from the criticisms made by Sahlins (1972), who suggests that Mauss’s analysis only explains why gifts might be repaid, not why they are given in the first place, nor why they have to be received.

(1970: 157). By comparing the American commercialised system with the British voluntary gift donation, Titmuss concluded the latter voluntary system was morally and practically superior. A commercial exchange in blood, according to Titmuss, exploits the poor and vulnerable members of society, because it appeals to the immediate self-interest of the donor, it motivates purely by financial reward, offering an opportunity to temporarily ameliorate the poverty of their environment. Therefore, under a commercial system the blood supply flows from poor to rich, subsequently lowering societal morality, and posing a risk to the health of the donor, who may be tempted to donate more frequently than is considered safe.³⁵ As a result, paid blood donation also poses a potential risk to the recipient. In a pre-AIDS era, hepatitis was a major concern with, at that time, no adequate detection of hepatitis in the blood. Detection was entirely due to the willingness of the donor to make known whether they were a sufferer – offering cash for blood, arguably led to some not doing so. Titmuss showed that between 4 and 5% of American blood recipients over the age of forty contracted serum hepatitis. Up to the time Titmuss was writing, no British study found a hepatitis attack rate over 1% (1970: 145, 148, 154 – 5). Thus Titmuss concluded the voluntary system was not only ethical, but also more efficient and safe. These arguments have had a considerable effect on public opinion and political action. In 1973, as a result of the combination of Titmuss's work, the Nixon Administration's National Blood Policy, and public opinion, the commercial blood supply was eventually phased out. At present, payments for either blood or organ donations are prohibited in the UK, the latter by the 1989 Organ Transplant Act.

Black Markets in Organs

Nonetheless, although most Western countries prohibit payments for blood and organs, reports that markets in organs exist appear regularly in the media. Organ commerce has been condemned by the World Medical Association, which prohibited such practices in 1994. Comparable to Titmuss's research, the desire for monetary gain appeals to the immediate impoverished circumstances of the donor. Scheper-Hughes, in comments not dissimilar to Titmuss's thirty years previous, suggests the movement of organs flows in one direction, "from South to North, from poor to rich, from black and brown to white, and from female to male" (Scheper Hughes *New Internationalist* 1998: 15). Most European, Asian, South American and Middle Eastern countries, carry out successful kidney transplants, though the success rates are lower in countries such as India, China and Brazil, which tend to rely on living donors. Such reliance on living donation may, in

³⁵ The American paid donors were typified by Titmuss as a group of "narcotics, dope addicts, liars, degenerates, unemployed derelicts, prison narcotic users, bums, the faceless, the undernourished and unwashed, junkies, hustlers and

part, be due to the country's lack of necessary organisational infrastructure to procure cadaveric organs, and due to religious and cultural beliefs regarding the status of the dead body. In India, there is no system for procuring cadaver organs and no brain death statute. Although commerce in organs has now been prohibited by legislation introduced in 1997, allegations persist that the trade continues in a larger, underground market. Meanwhile, the Internet has served to expand organ commerce globally. In 1999, an advert ran on the Internet auction site E-bay, offering a "fully functioning kidney for sale. You can choose either kidney. Buyer pays all transplant and medical costs." Bids reached \$5.7 million before the site was closed down (O'Neill, *Scotsman Magazine*, 10 March 2001: 16).

China, apparently, has capitalised on its death penalty legislation in order to increase the organ procurement rate. Reports suggest that transplants can be organised to coincide with executions (Higgins, *The Guardian*, 25 February 1998). Human Rights Watch and Amnesty International estimate such executions are the source for nearly 90% of the kidneys transplanted. Officials in China admit organs are taken, but only with the prisoner's permission, a statement received with scepticism by human rights groups. Such groups report the state routinely takes kidneys, hearts and valves, and corneas and sells them to, "medical visitors" from Hong Kong, Taiwan or Singapore, for up to \$30 000 an organ (Scheper-Hughes *New Internationalist* 1998: 16). In 1998, two Chinese organ brokers were arrested in the United States, one a state official involved in executions, for the attempted sale of kidneys, corneas, livers and lungs of executed prisoners (O'Neill, *The Scotsman Magazine*, 10 March 2001: 17).

Financial Incentives and Organ Donation

In contrast to an unregulated market of cash incentives to the living individual, economists argue financial incentives should be introduced in Western society in a regulated manner, with a "future market" based on financial compensation received after death, and subsequently paid to the deceased's estate (Cohen 1989).³⁶ Individuals would contract their organs to be made available after death, with variable sums paid to their estate, depending on each organ and tissue successfully removed. Thus hospitals would become "bailees" of the dead body, required to take as much care with it as with his [sic.] wallet and watch" (1989: 34). If doctors asked the deceased's relative's permission, which

ooze-for-booze donors" (1970: 114-5).

³⁶ Primarily commercialisation can be utilised in procurement, allocation or both. Most literature pertains to procurement, but Grady (1994) and Guttman (1991) discuss allocation and Hansmann (1989) both. One of the earliest proposals was from Schwindt and Vining (1986) who developed a model for a centralised, government system that would allow donors to contract, for a price, the delivery of organs at their death. Hansmann (1989) taking their lead, argued for an annual contract and finds a role for health insurance companies, rather than a lifetime contract that Schwindt and Vining (1986) proposed.

subsequently met in a refusal, the relative who was the named beneficiary of the organ sales contract could effectively sue them.³⁷ Cohen attempts to avoid both ethical and practical issues related to selling body parts. A future market is thought to undermine the immediate self interest that leads to a poor quality of supply, and the vulnerable and poor members of society are not pressured into ameliorating their situation by employing the resources they bodily own. In Pennsylvania, such proposals have already been put forward, with a fee of \$1000 offered towards funeral costs (O'Neill, *The Scotsman Magazine* 10 March 2001: 17). Though recognising the proposals to sell organs may seem to be, "the ravings of ghoulish law and economic fanatic[s]," Cohen insists such proposals are moral as they favour "the living over the dead" (1989: 51).³⁸ Any deep-seated antipathies to organ transplantation, he argues, can be likened to such tasks as cleaning public toilets. In such cases, "if sufficiently compensated," he would be able to overcome his "deep-rooted neurotic aversion to human excrement" (1989: 11). Making "ballpark estimates," of five thousand dollars apiece for major organs and lesser amounts for corneas, bone marrow and skin, Cohen concludes, "the problem ... is not at bottom psychological or religious: it is economic" (1989: 50).³⁹

THE NATURE OF THE GIFT

Although Cohen's future market avoids most of the ethical and practical issues raised by Titmuss's work, other factors can pose obstacles to the introduction of financial incentives. First, most developed Western countries have rejected such proposals. As outlined in Chapter 2, the 1989 Organ Transplant Act legislated against the receiving of payment for organ donation, due to the public outcry after the discovery in 1984, that individuals had entered the UK in order to sell their organs. Granted, legislation can be changed, however, the proponents of financial incentives also assume people are reluctant to donate. Yet, as shown in Chapter 3, reluctance to donate is only one factor among many that affects the donor rate, and the economists' proposals ignore the effect of hospital organisational dynamics, the rate of road traffic accidents, population density etc. Third, those who make such proposals do not know whether or not introducing financial incentives will increase

³⁷ Such sentiments were announced more recently by the bioethicist, John Harris, who argued that "a commercial market in live organs could be run ethically under strict conditions. A single purchaser, such as the NHS, could ensure there was no exploitation of poorer countries or illicit trade across continents and that the organs were distributed according to medical need" (Jenkins, *The Times* February 18, 1999).

³⁸ Peters (1991) justifies the adoption of a market approach by citing the financial gain for all concerned in the transplant process (physicians, co-ordinators, surgeons, social workers, hospitals, etc.) with the donor and family being the only participants not directly benefiting from the process.

³⁹ There is a more moderate stance that Kass (1992), Daar (1991) and Peters (1991) suggest a "reward gifting" which is viewed as a tribute towards the donation act. Pellegrino (1991) critiques "reward gifting" arguing that it is morally dubious and destructive, and priorities the interest of the family over that of the deceased. Murray also finds this indefensible and describes reward gifting as an "execrable oxymoron ... a euphemism employed by others in defending such plans" (1996: 108).

the donation rate.

Finally, selling organs will be compromised by values individuals attach to their bodies. Marshall, Thomasma and Daar (1996) show that applying economic incentives to the organ procurement system will always be negotiated within “cultural parameters constrained by several factors: beliefs about the physical body and personhood, religious traditions, economic conditions, and technological resources” (1996: 1). For example, in Judeo-Christian tradition the body is viewed as a sacred “vessel” of God. They argue that even disregarding religious representations of the body, socially the body remains “sacred.” Within a Durkheimian interpretation, “[T]he central, paramount value of the human person ... cannot in fact be a central, paramount value unless there is a zone of the sacred that constitutes it through collective taboos that mark it off from the profane ... The body is an integral symbol of the person ...” (Watts Miller 1996: 161). The body is sacred due to its intimate relationship to personhood. On one level, this may be why it is considered organs should be “gifted” – because the act of giving is considered a “sacred” moral act, that is in harmony with the “sacredness” of the gift being given. Thus the cultural values attached to the body can work in tandem with the values of gifting.

Economists, like Cohen, miss such cultural nuances. People are not only motivated by money and organs are not equated with cars, clothes or any other commodity definable in monetary terms. Becker argues that social scientists conceal their own lack of understanding of social behaviour, by obscure claims that such behaviour is determined by “ignorance and irrationality, values and their frequency and unexplained shifts, customs and tradition, the compliance somehow induced by social norms, or the ego and the id” (1976: 13). One can counter-claim that, the main assumption behind the economists’ proposals, that only “money motivates,” lacks any understanding of the sociability of individuals:

The narrowly economic view of people and their morality is deformed, shrunken and defective. It fails to understand why people value human relationships, how relationships based on and succoured by gifts are significant, and what genuine human flourishing consists in. The economic view cannot grasp why people would donate their own or their relative’s organs, or why people would object to markets for organs (Murray quoted in Younger, Fox and O’Connell 1996: 118).

IN THE SPHERE OF GIVING: THE MORAL ECONOMY⁴⁰

Whether or not introducing market incentives would increase the supply of organs is a moot point – what is interesting is that there appears to be widespread moral abhorrence of cash for organs. The significance of the present rejection of market proposals, in both blood and organ donation, can be linked to what has been conceptualised as the “moral economy.” Making money out of another’s need is a principle antithetical to the ideology of the moral economy, where the morality of action is emphasised. The term, initially used by Thompson in his work “The Moral Economy of the English Crowd in the Eighteenth Century,” (1971) referred to principles of fairness and custom that underpinned the late eighteenth and early nineteenth century food riots, when workers took to the streets to show their anger at further increases in the price of bread.⁴¹ Rather than the ensuing riots simply being caused by “uncontrollable hunger,” Thompson argued the mobs’ actions were informed by a “moral economy,” stressing a traditional set of social norms and obligations that the community has towards the individual in times of scarcity and need.⁴² The fundamental difference between actions in this sphere and actions in the political economy is, though both are constitutive of society, within a moral economy lateral and unilateral transfers have a non-contractual, non-commodifiable basis. Action is done for the sake of social relationships and other individuals, not for gain within the cash nexus.

Modern Moral Economies

Recently, the moral economy has been augmented and applied to contexts as diverse as areas of development in the Third World (Scott 1976), with an emphasis on the moral content of subsistence ethics and peasants’ perceptions of obligations and reciprocity; and to policing in the East-End of London (Hobbs 1976), with a description of the reciprocal relationships between police officers and offenders. It has also been applied to the evolution of genetics in the 1930s (Kohler 1991), where the moral economy enabled an understanding of material/cultural production (within every system of production there exists a corresponding “moral economy” to regulate access to the means of production/goods produced like scientific knowledge and subsequent credits for achievement). Also to women’s exchange in US. garage sales (Hermann 1996), and a discussion of the dependency of an increasing older population on the Welfare State

⁴⁰When discussing “moral economy” the intention is to identify morality within the specific context of production, distribution and consumption. Otherwise one would then be articulating morality per se and not in relation to the values and meanings attached to exchange.

⁴¹Thompson’s work in this area has been criticised by some social historians who argue that his analysis pertains to a unique time of social and economic intersection and therefore will not prove durable. For a further discussion of these criticisms and answers to them see Well (1994).

⁴²This is not to assume that the riots were class-specific or that some members were not concerned with taking advantage of the situation to their own benefits.

(Robertson 1997), and finally, a description of family gift-exchange behaviour at times of celebration (Cheal 1988), where it is argued that gifting solidifies personal and community ties. In contrast to the existence of the moral economy applicable in the context of close face-to-face social relationships, between kin and friends (Cheal 1988), fellow scientists (Kohler 1991), and communities of landed peasantry (Scott 1976) it has also been used to explain a generalised reciprocity, which helps to create a sense of community between strangers (Hermann 1996), and as an obligation on the part of others to help people they don't know (Robertson 1996).

What most of these approaches share, is an analysis of social relationships that has a non-market basis. Robertson suggests that taking part within a moral economy “decommodifies” reciprocity (1997: 440). Where individuals are embedded in the market, notions of reciprocity are viewed in distinctly instrumental, materialistic and commodified terms. One can tell, for example, when money, labour or commodities are exchanged. Yet, as Robertson asks, “how do we count or measure love, time, energy, kindness, shared memories, care - all the things which constellate human relationships and create community?” (1997: 440). What a moral economy highlights, is the existence of some human relationships that are not amenable to cost-benefit analyses. Market and moral economies generally follow different rules:

Only here [in the moral economy] can it be said that economic value does not enter into the picture, that intentions alone count; only here is it possible for the social mythology of voluntariness and freedom to be deployed against the realm of necessity, or for the idea to gain ground that relations exist for their own sake and have their existential meaning within themselves” (Berking 1999: 10).

In contrast to Thompson, Cheal defines “moral economy” in a narrower sense, as a system of transactions, which are socially desirable (moral) because such social ties are recognised and balanced social relationships, maintained (1988). Moral economies are grounded within “part-societies,” small worlds of interpersonal relations, which are at the emotional core of every individual's social experience. What is expressed in gift transactions, is an unconscious understanding of social order. Cheal demonstrates that people still spend large amounts of time and money on gifts at celebrations such as Christmas, and “gift-giving in fact makes a vital contribution to contemporary social life”(1988: 5). He suggests, gifts are no longer the primary means of mutual aid, but are rather a symbolic mechanism for managing emotional aspects of relationships. In other words, the transfer of

gifts is a feature of the institutionalisation of social ties (Cheal 1986, 1987). Cheal's analysis has similarities to the Maussian gift-exchange model, in the form and nature of the individual's "obligations." For example, his analysis pertains to gifting at ceremonial occasions, and at times of formalised gift giving, between kin members. At rituals, such as birthdays, Christmas, christenings etc., the donor can feel directly *obliged* by social custom and other family members to give and to reciprocate (Gerrand 1994: 136). This is a gift economy that, like Mauss's gift exchange, maintains pre-existing social relationships and kinship connections due to a perceivable strong normative obligation at such times to gift. Cheal is analysing gifting as an obligation within celebrations, where there is arguably a strong, social pressure obligating the gift. Further, the gift is given to someone who is known to the donor. So, whilst not disagreeing with his argument, it does little to suggest why anyone should give to another *outside* of his or her intimate social circle, or at a time when there is no ceremonial occasion or obligation to give. Moreover, the problem with applying the moral economy to organ donation is, that actions within such an economy are generally informed by custom and tradition, and tend to involve hierarchical power relations within face-to-face known relations, as Thompson's original example demonstrates. This is not the case with organ donation, an organ is given to unknown other with no hierarchical power system. This does not, however, challenge the argument that such actions can occur between unknown others within a moral economy, but requires two additional routes of analysis, first, empirical research and second, an investigation into how known are unknown others?

THE SOCIAL BASIS FOR ALTRUISTIC SYSTEMS

It can be argued that unknown others are "known." Arguably, the basis for systems such as organ and blood donation lies in the *essential social nature of our co-existence*. Procurement systems based on unreciprocated gifting, take advantage of the fact that people are intrinsically sociable creatures, not "asocial individuals" (Barnes 2000: 64). As a result, in the words of Adam Smith, "Conscience is a product of social relationships. Our first moral sentiments are concerned with the actions of other people. Each of us judges as a spectator and finds himself judged by spectators" (quoted in Wolfe 1989: 29). According to Smith, when judging one's own conduct it is not simply enough to imagine what an "impartial spectator" would say but how they would actually feel. We try to conceive, to "sympathise" with what it would be like in another's position. With the decline of local communities and tight, dense social ties of family and place, modern society is a society of unknown others. The "unknown other" may not be immediately accessible in either time or locality. Yet, as Giddens suggests, in describing the Durkheimian move from organic to

mechanical solidarity:

... the individual no longer shares the same characteristics as all other individuals in his society: he is more and more a particular differentiated personality. But at the same time that he is particularised with the group, he grows increasingly aware of the properties which he possesses in common with the rest of humanity (Giddens 1972: 9).

There is no paradox between the individual becoming increasingly differentiated, yet increasingly aware of their similarity to the rest of society. In modern society, faith and judgement resides not with God, but in the actions of others. Following Durkheim, it is society, the “secular God,” that is the “end and the source of morality”:

Moral rules are social in origin (‘the rules of morality are norms that have been elaborated by society’), they are general within a given society (‘there is a general morality common to all individuals belonging to a collectivity’), they presuppose human association (‘let all social life disappear, and moral life will disappear with it’), ... and they necessarily involve altruism (‘The basis of moral life is the sentiment that man does not belong to himself alone...’) (Lukes 1973: 22).

We are members of one body, a social body, and it is the social body individuals can act in reference to, not purely out of their own self interest. Essentially, as Titmuss’s results showed, individuals donated blood because they were aware of need through: general or individual appeals; wanting to help others; in case of their own future need; or indeed perhaps a combination of all three. Apart from an awareness of their own need, the common elements these reasons share is an awareness of the results their actions will have on *others*. In short, they are affirming their personal and social identity through acting in relation to social bonds. Elias, for example, demonstrates although we may not feel interdependent or tied to others, such subtle bonds are powerful forces. The “figuration” of people, is a term employed to argue that, “though we are alone, or perceive ourselves to be alone because we know no one in a crowd, we are still tied to this figuration of relations, still bonded to other people with whom we are interdependent ... (quoted in Burkitt 1994: 19).⁴³ Similarly, as Wolfe suggests:

⁴³ Even Adam Smith, who spent so much time on studying exchange and self-interest, still offered the “impartial spectator” and an environment of empathy (leading to sympathy) that allowed Smith to suggest that individualism can easily co-exist alongside a moral framework. That is, to “endeavour, as much as he can, to put himself in the situation of the other, and to

Because modern individuals are social and not just natural creatures, they incorporate into the self a generalised sense of society by contemplating the effects of their actions on others, just as, in nearly everything they do, they assume that others will similarly incorporate into *their* actions the effects of living together (original emphasis, 1989: 213).

One can argue that donor families donate, not just because of altruism, but because of self-interest and reciprocity. The system they take part in, however, is based on the sociability of individuals. What then of non-donors? Do they incur social stigma and embarrassment because of their failure to act in reference to the generic social bond? Moreover, do individuals in society judge them for potentially failing to save life? The limited amount of evidence presented in the last chapter, regarding how non-donor families felt about non donation (Tymstra *et al.* 1992, Burroughs 1998) suggest this is not the case. Both donors and non-donors are equally likely to regret the donation decision.

The issue for non-donors is they may feel transplantation transgresses the sacredness of the body. In short, the body and its parts are imbued with a symbolic and emotional importance, the transgression of such cultural standards, incurs emotional outrage, as evidenced by the public's reaction to the recent "retention of organs" episode. As the Alder Hey episode demonstrated, relatives felt that their right "to lay the dead to rest" had been violated (Chrisafis, *The Guardian*, Wednesday January 31 2000: 5). The paradoxical situation that organ donation gives rise to is, the sacredness of giving can conflict with the sacredness of the body.⁴⁴ In short *the production of paradoxes and parallels regarding the sacredness of gifting and the body is inherent to organ donation and transplantation.*

Therefore the economist explanation of market exchange can only be valuable in solving the problem of the organ shortage if, one first accepts, organs are simply material, commodifiable goods and not endowed with a social and cultural capital. And second, individuals are rational, self-interested utilitarians, and not relatives usually in the midst of extreme grief; both factors making commercial exchange inappropriate.

bring home to himself every little circumstance of distress which can possibly occur to the sufferer" (quoted in Wolfe 1989: 29).

⁴⁴ This explains why organs cannot be equated with commodities. For an object to be a commodity it must become "disentangled" (Callon 1999: 189), it has to be alienated from the giver and the prior environment. Organs carry with them, a degree of cultural symbolism and may continue to be associated with the donor.

SOCIAL EXCHANGE AND ORGAN DONATION

Gifting, it appears, is central to donating parts of the body for two reasons. First, introducing monetary incentives brings about an element of commodification to the body, an act that has always been controversial, as evidenced by some reactions to practices such as prostitution and surrogate motherhood. Second, it does not attempt to gain a monetary reward from another's need – a precondition of actions within the sphere of the moral economy. Rather the action is being undertaken because of the value of social relationships and reaffirms connections with others. Unknown others are known, in the existential sense that, individuals know them to exist and are aware their actions will have repercussions.

Monetary incentives have been rejected, both as solution and explanation, but the sociable premises of the present system of donation have been noted as a key to understanding the mechanisms involved. Explanations of organ donation behaviour that utilise such a basis are the social exchange and altruism paradigms. As regards the former, Fox and Swazey (1978) argued that the Maussian paradigm is useful in explaining organ donation, and have made an attempt similar to Titmuss's work with blood. Specifically, that the "freedom to give or receive an organ is neither absolute or random. These freedoms are mediated and governed by the norms of gift exchange" (1978: 5). The obligatory aspect of blood donation was questioned earlier, but does it apply to organ donation? First, Fox and Swazey argue there is an obligation to give and that one is compelled to donate an organ. Yet it is questionable, as in the case of blood donation, whether everyone who donates an organ is under the coercion of *obligation*. Obligation, at least in Titmuss's research, was not a significant finding, and implies that the individual has no choice in the matter, that the action is a duty, and that it is compelled and involuntary. In cadaveric donation, individuals and family members *can* and *do* refuse to give, as demonstrated by the relatives' refusal rate of approximately 30% (BACCN/UKTCA 1995). Moreover, it is difficult to see what the source of this obligation might be. Fox and Swazey do not attempt to outline what form it might take. The limited amount of research on the health professionals' role in an organ donation request demonstrates that health professionals do not use pressure or force to make relatives donate organs. To do so, would contravene ethical boundaries in modern medicine. In fact, studies have demonstrated that health professionals are occasionally unwilling to make an approach (Younger 1990). The source of obligation may be the individuals and families themselves, through the knowledge that there is a shortage of organs. Yet it is one thing for an individual to be aware of a shortage, and another for them to do something about it, as studies into the public attitudes and

behaviour regarding organ donation have demonstrated (King's Fund Institute 1994). Moreover, how does the individual translate this knowledge into obligation? Finally, can the obligation to donate be sourced to the deceased i.e. a duty to carry out their wishes? In short, if obligation does play a part, we would need to know more about the source and nature of it. It may be the case that there is a certain amount of obligation to donate, a person may die as a result of refusal, but as yet this is to be demonstrated.

Fox and Swazey further suggest the recipient is obligated by "normative pressures" to accept an organ. It would seem more likely an impending death would "obligate" the recipient to accept the gift. Public opinion surveys and anecdotal evidence from conversations with surgeons, however, suggest a minority of individuals will refuse organ transplantation for a variety of reasons, including religious and cultural objections (King's Fund Institute: 1994: 39). Rather than feeling "obligated," the primary feeling the recipient would experience is of tremendous joy and relief a donor had been located (see Simmons, Klein and Simmons 1987 for a more detailed discussion of recipients pre- and post-transplant).

Finally, Fox and Swazey suggest an obligation to reciprocate on behalf of the recipient. Yet, as they themselves admit, giving parts of the body is arguably an inherently *unreciprocal* gift with no physical or symbolic equivalent, and may result in a "tyranny of the gift"- a recipient can feel a burden of guilt through their inability to repay the donor. Several points can be made against the "obligation to reciprocate." First, as Gouldner suggests, the problem with viewing gifting as exchange is the failure to distinguish between two types of norms: reciprocity and beneficence. Because these may both be involved in gifting behaviour there is little effort to distinguish between whether people give gifts freely under some conditions or whether they expect a return (1973: 298). Mauss, especially, is singled out as failing:

... to distinguish the *motivation* from the *consequences*. He had missed the fact that action *initiated* in accordance with a norm of beneficence may lead to interaction in accordance with the different norm of reciprocity. While Mauss makes it clear that the giving of a gift commonly eventuates in a pattern of reciprocal exchange, he fails to note that this is *not* always the *intention* of the donor. If the donor happens to be oriented to the norm of reciprocity when giving, then the intentions and consequences of his action will more closely coincide. If, however, the donor is oriented to norms of beneficence, this may indeed motivate him to give a gift

without any consideration or expectation of a return from the recipient (Gouldner 1973: 299).

Further, an offer of thanks for the organs does not corroborate or finish the Maussian cycle - Mauss argued that the reciprocal gift should be of *equivalent worth or more*.⁴⁵ More recently, Sque and Payne (1994) have developed Fox and Swazey's work, arguing that because the market exchange model is inapplicable to organ donation, the gift exchange paradigm is appropriate. But, as O'Neill (1993: 10) pointed out, the:

... gift is made not to a particular recipient but to a stranger, a generalised other, or possibly the community in general. It is made as an impersonal, indirect gift. The difficulty in applying Mauss' gift relationship theory to donor family/transplant recipient relationships is that the theory is based on direct, personal exchange characterised by the absence of anonymity, where givers and receivers are personally known to each other. These features are obviously lacking with the necessary anonymity associated with the giving and receiving of an organ.⁴⁶

As Cheal states, "gift practices are, as Mauss suggested, rooted in custom and tradition. But gift customs are not fixed, for they have been affected by changes in the larger society" (1988: 3). Mauss's analysis pertains to non-industrialised societies, and the relevance of his work is questionable when applied to modern forms of gifting. Both blood and organ donation are organised through systems that block the potential for exchange, through anonymity between donor families and recipients. This makes explanations that stress the obligation to donate appear tenuous. It is not to suggest there is no sense of obligated donation, or that people feel helpless to repay the gift, rather it has not been adequately demonstrated by research into cadaveric donation.

Social Exchange, Obligation and Living Donation

There are some situations where obligated donation does appear to exist, and where the existence of face to face relationships implies a more duty-based form of giving. The social exchange analytical framework may, in some respects, be lacking when applied to

⁴⁵ Martin and Meslin (1994) while agreeing with the argument presented here, that organ donation does not fit within the Maussian paradigm of social exchange, therefore conclude that the ideology of donating an organ as a gift, should be replaced with a presumed consent system: that is organs should be taken as opposed to given.

⁴⁶ The gifting of organs *can* lead to the construction of new social relationships, a factor which leads the transplant community themselves to stress the importance of anonymity between donor and recipient. It is often the case that the recipients want to thank the donor families. To protect anonymity, the transplant co-ordinators will often pass on letters to the donors and vice versa from donor to recipient.

cadaveric organ donation due to the principles of anonymity and voluntariness that gifting organs rests on. However, there is one area of organ donation where the concepts of close ties and obligations appear to apply. According to Page (1996), the strength and existence of emotional bonds that tie family members together imply an obligatory system of relations. Acts then may be considered as, “duty to one’s own” or “obligations to the family” (Page 1996).⁴⁷ It is well documented in living donation, when an individual requires a kidney, members of the family often approach the medical staff before they have a chance to make a request. (Simmons *et al.* 1987). It is probable donation stems from a strong sense of responsibility and emotive bonds to the family, and Fox and Swazey (1978) demonstrate this in their research into living donation:

The characteristic structure and dynamics of the family system in a given society influence not only the degree to which various relatives are expected and motivated to donate an organ, but also the amount and type of strain to which they will be exposed if they either offer or refuse to do so (1978: 21).

In fact, it may well be in the self-interest of the individual family member to donate, so as not to incur any sanctions from other family members. Feminist writers have sought to show that women, either in a family or couple, who offer help are more likely to do so because of a “compulsory” altruism rather than a “voluntary” one. Gilligan (1982) argues that in society there are two moral voices; the “ethic of justice” and the “ethic of care,” the former being associated with men. The latter, which women (especially mothers) are thought to exhibit, emphasises caring for the well being of others. Although Gilligan is making a rather contentious and essentialist claim for a “female morality” based on caring, it might be relevant to organ donation, *if* women are more likely to donate their relative’s organs than men. There is no available evidence to suggest if this is the case. However, given the institutionalised importance placed on parental, especially maternal love in this society, it would seem conceivable.

The social circumstances surrounding living donation are significantly different to cadaver organ donation. First, in cadaveric donation, there is no relationship between the organ recipient and donor; they do not know each other (due to anonymity as an integral feature of cadaveric donation). Second, there may be a strong social obligation to give to another family member, again, in cadaveric donation it is questionable whether anyone is obliged

⁴⁷ I am not denying that there are times when family members do perform what can be considered altruistic acts. Rather the suggestion is that such acts are generally done out of obligation.

to donate his or her organs. Yet these two features of organ donation - anonymity between donor and recipient, and the lack of direct obligation to give do imply that although the social exchange model may be applicable in the case of living donation, its relevance is dubious when applied to cadaveric. What seems significant is that the closer the bond to the recipient the more obligatory the act appears to be. On the other hand, more distant ties suggest a less duty based, but more empathic concern, with the “known unknown other.”

Altruism and Organ Donors

Sympathy - the one poor word which includes all our best insight and our best love
George Eliot, *Adam Bede* (Quoted in Collard 1978).

Truly to love one's neighbour ... is to see things from the neighbour's point of view, to align one's purpose to his [sic] own. If this involves sacrifice, then what is sacrificed must be in the nature of a gift rather than a commodity; it must embody the *person* of the giver. Perhaps we may call this altruism ... [I]t is to say that persons are united in their amity, not divided by it ...altruism would [then] come to characterise the mutual constitution of persons (Ingold 1986: 289).

There are several, central features that potentially aid reaching an understanding of the underlying social and cultural mechanisms that cadaveric donation is embedded in. Firstly, the lack of monetary reward implies the donation act is undertaken for reasons other than financial gain. Secondly, introducing financial incentives may subvert i) the sacredness of the gift and, ii) the principles of the moral economy that stress the importance of relations for their own sake. Third, the rules of anonymity and voluntariness that cadaveric donation rests upon imply, though not conclusively, that the obligations attached to the social exchange model may be lacking. The fit of this model to familial living donation is, however, compelling.

In contrast to Titmuss's thesis that altruism *strengthens* social bonds, it may be the case that altruism is an *expression* of generic social bonds. The existence of the “other” has to be imagined, because they are unknown, while simultaneously being known to exist.⁴⁸ The ability to empathise and sympathise is based around a stranger's need, an individual the donor is never likely to meet so therefore, has to be imagined. These apparently voluntary, unreciprocated acts directed towards the care of others, show that the performance of such

acts, may be done purely for the sake of the actions themselves and not necessarily for intrinsic gain. If there is some form of gain, such as aiding in the grief process, it is likely this was an unforeseen consequence of the donation action and is a small return for the actual gift. Gerrand suggests that, organ donation should be considered as a form of charity, due to the similarity of charitable acts and donation (1994: 147). For example, most acts of charity are considered supererogatory, are usually considered voluntary and “with a genuine willingness to help someone who is usually not known to the person performing the charitable act, and who has a particular need” (Gerrand 1994: 147). Gerrand’s analysis takes into account that there is little, if any reciprocity, involved on the part of the donor:

For the giver, ... the expectancy of reciprocity is non-existent or negligible. As the motive/reward of action is in the act itself, the sacrificial giving can be analysed as the reinforcement of a sense of generalised (social) identity of the giver, as a socio-psychological affirmation as giver (active role) enacting the socio-culturally meaningful values of his[sic] reference group (Machado 1998: 61).

The fundamental, yet obvious tenet of this argument is that individuals are first and foremost social beings. They can contemplate or imagine the effects of their actions on unknown others. Of course, it would be a mistake to think that this is purely altruistic, as there may be elements of reciprocity and self-interest to donation. Although individuals may donate because they can imagine and empathise what it is like to be in the recipient’s situation, they may also donate in the hope if they found themselves in a similar position, someone else would do the same for them. Equally, donor families may be against donation and/or simply carrying out the wishes of the donor, and this again questions the altruism explanation. Is it too far a stretch of the imagination to suggest some donors donate, not because of altruistic reasons, but because of misanthropic ones? That is, donation occurs because they did not especially care about their relative?

Although perhaps tenuous, what this suggestion serves to demonstrate is that, though the basis of donation systems lie on the sociability and interdependence of individuals, this does not mean all individuals are acting with the welfare of another foremost in their mind. It may be their own welfare and imagining what it would be like if they were in the recipient’s place- like some of Titmuss’s blood donors, they asked themselves what if they were the ones in need? The point is, although an altruistic system may offer a collective

⁴⁸ An idea perhaps not unlike Benedict Anderson’s idea of an “imagined community” (1983).

means of procuring organs or blood without subverting the sacredness attached to the gift, it is misleading to equate the collective system with the motivation of each and every individual that takes part within it. Doing so not only removes the individual from the immediate social context of donation, but as an abstract explanation for all donating behaviour, leads into theoretical cul-de-sacs, offering to explain all donating behaviour, and therefore, none. In other words, this chapter does not deny the existence of altruism, nor is it cynical regarding the part it plays in organ donation. Rather the aim is to temper and problematise the claim that donation occurs purely for altruistic reasons with the caveats that obligation, self-interest and reciprocity can also play a part (this will be returned to in greater detail in Chapter 7, when the donor family findings are presented). Although relatives donate because as social actors they can imagine, empathise and sympathise with the need of others, and that these others can, and are expected to do the same, this may only offer a partial picture. Moreover, the relationship between donation and obligation is unclear – it seems more likely that obligation is affected by and dependent on the closeness of bonds. A tight kinship network that implies an obligatory duty based system of aid, whereas the looser the social bonds, the greater is the likelihood of anonymous and voluntary giving. If obligation does play a part in cadaveric organ donation what is its source? One fruitful avenue to explore, is the role of the deceased's wishes on the matter. If obligation is constitutive of family relationships, do such obligations based on close knit ties continue past death? Here lies a potential explanation, which will be returned to in later chapters.

SUMMARY - THE "OTHER" IN MODERN SOCIETY

How is it, that society and the individuals in it can necessarily co-exist, without as yet, disintegrating into a "post-modern" vacuum of egoism, self-obsession and individual gain? Without wishing to over-generalise, the existence of practices such as organ and blood donation, of philanthropy and charity suggest, that there is a morality that stresses the cohesive, non-contractual and empathetic side of society, which may be as necessary for society as conflict and individualisation appear to be today. The "sacredness" of moral phenomena, of "sympathy for all that is human, a wider pity for all sufferings, for all human miseries, a more ardent desire to combat and alleviate them" persists, (Durkheim quoted in Giddens 1972: 23). Although the pursuit of self-interest and individual gain may have led to a high level of prosperity in most Western societies, co-operation can co-exist (Singer 1999: 44). Despite the ubiquity of markets and market logic, departures from it, such as philanthropy and charity, persist and require explanation.

The implications of gifting, at least in the context of organ donation, demonstrate non-commodified relationships, where actions are done for their own sake. It is in this unexplored social world that the values of love, friendship, generosity, and altruism take place. Helping others in need occurs here, because it is coming to the need of others that is the fundamental premise, not exploitation and profit. Here, again, is the sacred world of gifting and the gift, of a rejection of market values, where an individual can act in favour of the social bond. As Hume suggested:

The mutual dependence of all men is so great in all societies that scarce any human action is entirely complete in itself, or is performed without some reference to the actions of others, which are requisite to make it answer fully the intention of the agent ... In proportion as men extend their dealings and render their intercourse with others more complicated, they always comprehend in their scheme of life a greater variety of voluntary actions which they expect from the proper motives to cooperate with their own (quoted in Wolfe 1989: 15).

The organ donation system is premised on the sociability of individuals, and participation in such a system is constructed on voluntary, anonymous and unreciprocated giving, and this may imply altruistic action, but it does not imply altruistic motivation. In this chapter, I suggested organ donation and transplantation produces inherent paradoxes and parallels – of how organs carry connotations of sacredness and emotional value attached, that may work in tandem with the sacredness of gifting, but can also produce tensions. This, it was argued, is why non-donor families may not incur social stigma for refusing donation – it is understood the costs are too high, the transgression of cultural values attached to the body too violent, the resultant pain too much. In itself, this emphasis on the “sacredness of the body” raises further puzzling questions, to be addressed in the next chapter. For example, in an increasingly secular and material society, why is it the case that the values attached to the body persist? Given, religion seems to play such an insignificant role in modern British society, surely it is the case that, “when you’re dead, you’re dead?” Why then is the deceased’s body not necessarily equated with that of any corpse, and thus treated the same? Why do some organs, e.g., the heart, provoke strong, emotive reactions, as was the case at the outset of Alder Hey? In the next chapter, attention shall turn to the gift, “the body,” and I will argue that beyond the body, organs and death, lies a social and cultural symbolism that intersects organ donation. Inadvertently, what procedures such as organ transplantation raise, is questions about the nature of our relationship to our own bodies, about our embodiment as a person within a living or a newly dead body. In short, the

contradiction between organ donation and transplantation will be developed further in order to demonstrate that this is not just a case of removing an organ from one individual to be placed into another.

CHAPTER 5: ORGAN TRANSPLANTATION AND DIS-EMBODIMENT

She was dead. Her consciousness was destroyed. But not her life ... that delicate life had merely stopped, it floated, filled with unechoed cries and ineffective hopes with sombre splendours, antiquated faces and perfumes, unforgettable and self-subsistent, more indestructible than a mineral, and nothing could prevent it from having been, it had just undergone metamorphosis. "A life," thought Mathieu, is "formed from the future just as bodies are compounded from the void."

J. P. Sartre, *The Age of Reason* (quoted in Lamb 1985: 83)

Introduction

Since the 1980s, there has occurred a rise in sociological interest in the living body. At the same time, there has occurred a congruent increase in interest regarding death, dying and bereavement (Seale 1998, Hallam, Hockey and Howarth 1998). Despite this, there is little dialogue between theorising death, and theorising the dead body (Hallam *et al.* 1998: 1) and little attention given to disembodiment, therein. The central aim of this chapter is to address this deficiency, and attempt to forge such a sociological theory, through examining organ transplantation. This, it will be argued, allows the sociologist a valuable and unique opportunity to discover more about people's beliefs concerning their own and others bodies, both living and dead. Because the ultimate aim of donation is the removal of body parts from one human being, in order to be transplanted into another, studying organ transplantation permits insights that contribute to sociological theorising regarding the body, its constituent parts and eventual demise. Donating organs, for example, raises questions about the nature of our "embodiment" a term that signifies the relationship between mind/body, or more commonly, person/body (Lambeck and Strathern 1998: 6). The conceptual axis around which this discussion swings is, "embodiment," a term referring to a person's experience of their own body and whether individuals feel they *have* a Cartesian body, or the alternative monist, holistic view, whether a person feels they *are* a body.

Theoretically, I will argue that the definition of the body and organs, as well as death and the dead body, though biological events and entities, are socially constructed through differing social practices, discourses, and beliefs surrounding them. That is, both the monist and dualist views of embodiment are socially constructed depending on social

interests and/or cultural belief.⁴⁹ The bereaved will have a tendency to view the body, at the moment of death, as monist. The dead body continues to represent the person who once lived and interacted in the previous social world. In organ transplantation, this causes profound difficulties, as the relatives have to confront the “living” appearance of a brain stem dead body and accept that surgical procedures are required to procure organs.

The power of (previous) social relationships is, again, emphasised in this chapter. Whereas the last chapter discussed social bonds in relation to the nature of obligation, the central claim here is that the bereaved continues to have such social bonds to the deceased even after death, regardless of any religious affiliation. Simply put, in a secular, material world, *bodies die, relationships don't*. In support of such a claim, evidence suggests that biological and social death need not occur at the same time and a person can become detached, or dis-embodied, before death (Glaser and Strauss 1965, Sudnow 1967). Therefore, if a person can socially die prior to biological death, then the converse is also true - the person can continue to be socially present after (Klass *et al.* 1996, Mulkay and Ernst 1991, Walter 1996). In the context of organ donation, this can affect the relative's decision to donate or not, as statements such as “*it's what they would have wanted*” imply. Post-donation, the deceased's continuing social presence may have implications for the bereaved. The social representation of the deceased may be complicated via the knowledge that parts of the deceased continue to have a physical presence.

To begin, a discussion of the way dualism and monism are conceptualised in the literature is given. Evidence is then offered from previous studies of organ donors and recipients, demonstrating that certain organs, such as the heart and eyes, are imbued with a social and cultural significance, in spite of opposing medical reductionist discourse. Further, studies have shown that on occasion, recipients behave as if the organ they have received contains the personal characteristics of the donor, suggestive of a monist view of the body, where personal and corporeal identity converge. This theme of monism continues in the discussion of the change in the way that death is confirmed, and the medical and lay reactions to it. Essentially, cessation of heartbeat, the traditional means of ascertaining death, has been superseded by a brain-oriented definition. Further, a country's acceptance of brain stem death is, in part, based on the extent to which Dualism is embedded in belief

⁴⁹Nevertheless it is not the position here that language or culture alone somehow “constructs” the body, death or organs. Here, the biological basis of the body is not denied (nor the claims for its social construction exaggerated). To a degree, this may be “essentialist”, but as Craib (1995: 152) asks is it “any more essentialist than saying that nearly all human beings have two arms, but what they do with those arms varies culturally and historically?” On the other hand the body, is *not* just a given biological entity, but is also understood through a cultural and social lens. “Human beings do not simply apprehend the natural world as a given, since nature is always mediated through culture” (Turner 1996: 61).

systems. In Japan, for example, brain stem death was only accepted relatively recently. Arguably, this is due to how they perceive the relationship of body and person, where the person continues to socially exist even after death, a phenomenon that I argue can also be found in Western societies. The fundamental premise in all of these arguments is that the social not only exists alongside and upon the biological, but can also persist beyond.

Dualism/Holism

Organ transplantation, unlike any other medical procedure, relies on one of the most remarkable of resources, body parts. Therefore examining the phenomenon of transplantation, the taking and integrating of organs, offers the sociologist an exciting opportunity to examine peoples' beliefs about their own and other bodies. Of course, the "body" as a subject for social theorising has received increasing attention within the social sciences (cf. Shilling 1983; Synott 1993; Turner 1996). Turner (1996: 37) however, notes the absence of a focus on embodiment within sociology, arguing that academics should recognise that people both, "*have*" and "*are*" bodies.⁵⁰ "*Having*" a body, is a perspective inherited from the Cartesian, Dualist version of a mind/body split. Accordingly, the body is a material, mechanical entity, separate from what Descartes terms a "soul." "*Being*" a body, implies that the person and body are each synonymous with the other.

Yet which do people feel? They have or are a body? Or can both simultaneously exist? Turner (1996) appears to think so, though the situation may not be as clear cut. As far back as the nineteenth century, William James described his uncertainty whether the body is an essential part of the person, or alternatively whether it is something owned or possessed:

Our fame, our children, the works of our hands, may be dear to us as our bodies are, and arouse the same feelings and the same act of reprisals if attacked. And our bodies themselves, are they simply ours, or are they us? Certainly men have been ready to disown their very bodies and to regard them as mere vestures, or even as prisons of clay from which they should be glad to escape (James, W. 1890 quoted in Belk 1990: 140).

Then are our bodies "mere vestures," or vessels in which the non-material, intangible source of personhood is housed? It appeared so for Descartes, who concluded that:

⁵⁰Turner argues that individuals are referred to euphemistically by sociologists as "social actors" located in their "social location" and "structure" (1996).

... I possess a body with which I am very intimately conjoined, yet because, on the one side, I have a clear and distinct idea of myself inasmuch as I am only a thinking and unextended thing, and as, on the other, I possess a distinct idea of the body, inasmuch as it is only an extended and unthinking thing, it is certain that this I [that is to say, my soul by which I am what I am], is entirely and absolutely distinct from my body, and can exist without it (Wilson 1993: 214).

“This I,” is separate from a body that is merely a vehicle for the intangible, non-material substance of self.⁵¹ The body as a machine, and therefore an assortment of disparate, interchangeable body parts is a view quite compatible with organ transplantation, and one generally advocated by certain groups within the medical profession.⁵² Organ transplantation is therefore akin to stripping parts of a car, after the driver has got out, and organs can be considered in light of this (i.e. the heart is the “engine” or the “pump” etc.) However, this reductionist view of the body as mere machine is not the only one available (and as we shall see in a later discussion of countries such as Japan, an implicit cultural rejection of Cartesian Dualism has contributed to controversy regarding the introduction of organ transplantation).

Holistic Views

As Belk (1990) suggests another metaphor may also exist, a view alluded to previously by James; the body is central to our identity, *the person is the body*. Donating parts of the body is therefore donating parts of the person. Unlike the view of the heart as a, “pump” or “engine,” for example, parts of the body have been traditionally linked to personal identity. Organs are not merely biological entities, but are surrounded by an array of cultural beliefs regarding their relationship to personhood. Lamb suggests, “[C]riteria for personal identity, unlike the criteria for life, can be based on either fictional or real concepts of bodily image and organic continuity” (1985: 89). That is, identity is, in part, based on how we view the relationship between corporeal and personal identity, and history, tradition and custom can influence this, as well as science and medicine.

⁵¹ Descartes was apparently loath to equate the brain as the site of self, saying that “One thing is certain: I know myself as a thought and I positively do not know myself as a brain” (quoted in Manning Stevens 1997: 277). In part, this is why when speaking of embodiment, it is necessary to look beyond brain/body interactions to what people themselves experience as “embodied” and like Descartes most people do not experience themselves as a brain, but as having an identity as a person or self.

⁵² For simplicity I have used the terms “medical professionals,” “transplant community” and “lay public” while realising that these are artificial constructs, and do not take into account differences and hierarchies therein.

Organ Restriction

Studies have shown individuals unwilling to donate a particular organ, perceived the organ as more mysterious and sacred (Fulton *et al.* 1987, Wilms 1987). On the basis of such findings, Belk (1988: 157) suggests that, individuals are psychologically more likely to “cathect” (charge matter with emotional energy) those things considered important to identity, such as eyes and the heart.⁵³ Our eyes are probably the most distinguishing feature of the face, and unlike other facial features, may not change significantly, throughout the course of the lifecycle. Symbolically, the eyes are related to a person’s character, they are “the windows of the soul” and statements such as, “being able to see it in her eyes” and, “failing to meet someone in the eye” (both equated with a person’s dishonesty) are common metaphors used in relation to a person’s character.

“Being a Body” – the Heart

Throughout history, the heart has endured as the symbol of personhood, and continues to have powerful resonance today as a symbol for emotion, love, will and courage. Like the eyes, the heart is used widely in everyday rhetoric, for example “to love with all my heart,” a “heart to heart talk,” to be “heart broken,” and “to take heart.” One wonders why the symbolism of the heart survives in the face of scientific and physiological explanation to the contrary, that the brain is the site of personhood? Manning Stevens (1997) suggests that, as it is now known the brain is the site of consciousness, and consciousness can therefore be explained in purely physiological terms, the heart is free from any “scientific” discourse of the self. It can be allowed to remain in its metaphoric space, “symbolising the conjunction of body and soul” (1997: 276). Indeed, the first heart transplant caused unprecedented media attention because, as Helman (1991: 3) explains, “for the first time one of the most important metaphors for personhood had been cut out, handled and cleaned, and then placed inside the body of another individual. In a few historic moments, the borders of one human body had been breached by the symbolic core of another.” This caused concern for the wife of the first heart recipient, Louis Washkansky:

It started with “The Man With The Golden Hands,” which is how Louis Washkansky, chatting in Yiddish to his wife, describes Christiaan Barnard who performed the world's first heart transplant on Louis. He died a couple of weeks later ... At first Louis seemed to be doing wonderfully well. She was not allowed to see

⁵³ Yet, as Belk himself admits, not all people view their bodies as equally central to their identities and not all organs are treated with the same symbolic importance. For example, women, suggests Belk (1990: 143) are more likely to cathect objects than men and although he quotes studies to validate his argument, does not offer an explanation as to why this might be the case.

him until three days after the operation ... *"I was very apprehensive because I thought his personality might have changed, not realising that it is the brain that makes the person. I was happy to see he was the same Louis"* ("A Knife To The Heart," BBC1; 31. 4. 96 emphasis added).

The unintentional consequence of such symbolism is that relatives of organ recipients may be concerned about a personality change. Occasionally these type of beliefs can complicate the recipient's own physiological and psychological acceptance of the organ.

Psychological Effects on Recipients

Recent evidence suggests a, "confusion of personal identity, implicit in the thought of walking around with someone else's liver or heart" (Kass 1992: 74). Some recipients, such as Clint Hallam, recipient of a hand transplant discussed in Chapter 2, are affected by what can be termed a "psychological transplant" existing alongside the physiological one. These are documented, but not well researched incidents, and it is unknown to what extent the phenomenon of psychological transplants occurs. In the formative years of organ transplantation, Castelnovo-Tedesco reported a much higher level of psychosis occurred after transplantation, heart or otherwise, than any other major surgical operation, including those operations where amputation had occurred, suggest an organ *gain* is more traumatic than an organ *loss* (1973: 350). However, this was a period when organ transplantation was in its infancy, and there was little known about the effects of receiving a transplant, not only psychologically, but also physiologically. These studies may therefore be unrepresentative, and a reflection of the uncertainty at that time.

Other studies conducted thirty years later from interviews with forty-four heart recipients found that thirty-six of the recipients did *not* have any problem with accepting the transplant, and did *not* perceive it as having anything "foreign" within them (Bunzel *et al.* 1992). Four of the patients, who had received female hearts however, were concerned about whether receiving an organ from a different sex would have any repercussions (1992: 1153):

Yes, that stubborn woman, she didn't want to subordinate herself but now it seems that we have worked it all out between ourselves

My heart is my [female] slave. I am mainly interested in her performance.

Two other respondents acted as if the donor was still alive in them (1992: 1153):

Sometimes I can't really believe that I have another heart. I always say to it, this is my little lassie, and I have the desire to protect her. Somehow I feel as if she were not dead at all.

I'm thinking about learning how to ride a motorcycle. Now he has turned 19, he is allowed to. I'll teach him that too. Now the serious part of life will begin.

Two issues can be drawn from this. First, the gendering of organs, where the male respondents' comments demonstrate because the heart came from a female donor, they seem to believe female characteristics may have been passed on ("that stubborn woman" and "interested in her performance"). Second, the youth of the donor appears as a preoccupation ("now he has turned 19" and "my wee lassie"). The organs received, appear to be synonymous with the donor who donated them, who apparently "may not be dead at all" but continues to "live" in the recipient.⁵⁴ In other words, the person and body are believed to converge; parts of the body are therefore parts of the person. More recently, Sharp (1995) has suggested, the integration of an organ into a recipient can result in a "transformative experience;" it can alter the recipient's sense of self, with some individuals struggling to redefine their identities. Her ethnographic evidence, from a study of twenty six recipients, showed there was a "permanent sense of being renewed or healed [which] contributes to a sense of wholeness." The majority of recipients stated that, they had experienced a "new lease of life," and felt stronger and younger. One lung recipient told her:

I wasn't myself before – you get into your own little world. I couldn't wash my hair, eat or even talk without losing my breath. My brain didn't get enough oxygen so I couldn't think straight (Sharp 1995: 372).

Sharp's usage of such examples demonstrates the, "depth to which transformations are felt" (Sharp 1995: 372). However, precise numbers of how many recipients felt like this are not offered so it is difficult to gauge how extensive such reactions are. Neither does she suggest that feeling "stronger and younger" may be ubiquitous to any patient after a life-saving operation. It is normal, if not desirable, that patients will enjoy a significant increase in the quality of life (Lock 1995: 394).

Regardless, attention should be drawn to the fact that some recipients may be affected by cultural beliefs regarding the relationship between personal and bodily identity, believing characteristics of the person are "embodied" and carried within transplanted organs. More

⁵⁴ It would be interesting to see whether the phenomenon of "psychological transplants" relates purely to cadaveric donation or whether similar reports can be found in those recipients who receive organs from a living donor.

evidence regarding the monist nature of embodiment can be found in the reasons that donor families give for donation. By agreeing to donate, some families believe the act of donation can in a sense, allow the deceased to carry on physically living. Fulton *et al.* (1987) affirm this in their study, which found donor families donated as a means of allowing parts of the deceased to gain, “physical immortality” albeit temporarily until the recipient’s death (Fulton *et al.* 1987).⁵⁵ On the other hand, some relatives may object to donation for precisely the same reason, that is, they do not want something considered sacred and integral to their deceased relative becoming part of another. In this understanding, donation may be considered to have too high an emotional cost to the family.

The evidence presented so far suggests that, for some donor families and recipients, it may not merely be a question of changing one organ for another. The way we feel about our bodies “is deeply rooted in religion, arts, and poetry,” making us “prisoners of our ancestors’ pictorial fantasy” (quoted in Bunzel *et al.* 1992: 1151). The explanation for these reactions to organ transplantation lies in the belief that the person and the body are synonymous. This accounts for the fact that some recipients and donor families believe personal characteristics can be transferred through the organs.⁵⁶

Medical reaction to Monism?

Medical professionals deny this integration of personal and bodily identity and organ physiology. Such a denial may be symptomatic of more general differences in how the medical professional and patients view a person’s biological make-up:

Part of what makes the patient’s self-description unintelligible to the biomedical physician is the practitioner’s tendency to take the metaphoric construction of the illness experience for literal statements within the empirical world of biomedicine. Language is treated not as personal expression but as a transparent code. But “blood” for the patient [who regards it as a carrier of possible character contaminants] is not “blood” for the physician [who regards it as a neutral chemical cocktail]. The inability to see the metaphoric and contextual basis of discourse limits the physician’s comprehension of the patient’s life-world (Sinclair 1996:14).

⁵⁵ This “part for whole” representation is also noted in Hallam *et al.* (1999: 68) when ashes or body parts are disposed of, in absence of the whole body.

⁵⁶ Although it is unclear how the transference of personal characteristics takes place.

Significant differences in medical professionals' and patients' discourse of the body are arguably symptomatic of wider ontological questions about the nature of embodiment, personhood and corporeal identity. This is not to suggest all medical professionals hold a Cartesian, Dualist view of the body, and conversely all members of the public hold an integrated, holistic belief of body and person. Such metaphors are "entwined" as health professionals themselves are, "heirs to ... cultural tradition," just as lay people can and do use the mechanistic language of medicine (Birke 1999). However, it would be naïve to posit medical, Cartesian objectivity on the one hand, and lay, monist, subjectivity on the other, especially when issues relating to defining death arise.

THE SOCIAL CONSTRUCTION OF DEATH

Medical and Lay Perspectives

Just as some organs are imbued with a degree of social significance, due to a cultural belief system that stresses an integrated view of corporeal and personal identity, so too is the dead body. For the bereaved, the body is the location of personhood, it is where sentiments of love and loss can be expressed and subjective emotions, thoughts, and practices about death articulated (Prior 1989). As shown in Chapter 3, some families may not want to donate organs because this involves surgery to the dead body (BACCN/UKTCA 1995: 19). Yet how can one harm someone that is dead?

Perhaps because "we think of the dead as the persons they were ..." (Callahan 1987: 347). This can be historically traced to the eighteenth and nineteenth century, when death rituals and customs seemed to revolve around a belief that, for an undetermined amount of time after death, there was a tie between the body and the personality/soul (Richardson 1988: 7). Richardson discusses how, in this era, with the rise of anatomy and a consequent need of bodies for surgical dissection, the number of corpses provided from public hangings, was no longer enough to meet demand. Such a practice of dissecting corpses of criminals for dissection had already met with public furore and riots when the hanged body was removed to the Anatomy schools. However, an increased demand for more bodies brought with it an illegal trade in dead bodies. Grave robbing took place with exchanges established between body snatchers (the resurrectionists) and surgeons. In order to deal with the ensuing public outcry, the 1832 Anatomy Act legislated the provision of bodies of the poor for dissection.

In Britain, this tradition of "non interference" continues, and the deceased's body must be treated with respect and dignity. An indication of such strength of feeling is demonstrated

in the Alder Hey hospital cases, where organs were retained after post-mortem examination without the families' permission. The subsequent outrage reported in the media testifies to the intensity of feeling attached to organs and the integrity of the corpse. One father, condemned what he termed a "barbaric practice," and called an end to "unnecessary mutilation after death" (*Independent Saturday* 14 December 1999: 1). Similarly, photographs published in British national newspapers, of seven dead bodies lying on a floor in Bedford Hospital provoked public outrage not only because of what it suggested about the state of the National Health Service, but the perceived disrespect to the dead body (Boseley *The Guardian*, Tuesday 16 January 2000: 3). Yet, in an increasingly secular material society, where the dead body is arguably nothing more than a collection of "spare parts" what then of this concern regarding its treatment?⁵⁷

Respect for the Body, Respect for the Person

In modern times, as Sanner (1994b) suggests, "treating the dead body respectfully seems to take on the symbolic meaning of showing respect for the individual who once was" (1994b: 1148). Skeletons, for example, bear no resemblance to the person that once was, thus they do not provoke strong, emotive responses. Without such symbolic meanings of respect, "progressive" practices such as the one Gaylin (1974) proposes, might well be introduced. Brain stem dead individuals, or "neo morts," he argues, can be used for beneficial medical procedures, such as drug testing, or for medical students to train on and, of course, as an unlimited source of organs for transplantation. In these "body farms," row upon row of pink, apparently breathing, individuals lie recognisable as the persons they once were. The reaction to initiatives such as this, is comparable with the backlash in 1978, when it was discovered that corpses were being used (with the families' permission) to improve car safety. The outrage and political rows that subsequently broke out in the United States, led to such experiments being banned, and the development of the "crash test dummy" (Feinberg 1985).⁵⁸

There is a strong social and cultural significance attached to the body and its parts. Despite technological advances that can make use of dead bodies, because of past ties with the

⁵⁷ Some authors (Verble and Worth 1999) have suggested this fear of mutilation is a form of "blood phobia," a modern form of a primate genetic disposition that aided human survival by avoiding dangerous aspects of the environment. Not only is this argument completely unsubstantiated by empirical evidence, it does not suggest how only some individuals or groups i.e. parents are particularly affected. Neither does it differentiate human reactions regarding the destruction of the body, for example autopsies and dissection.

⁵⁸ Of course this construction of non-interference and respect to the dead body pertains mostly to Western societies. For example, when a father dies with the Melanesian Triobranders the sons have the important job of "...sucking the putrefaction from the bones of his exhumed corpse and washing them of rotting flesh in the sea ... The bones are then shared out ... and may be made into ornaments to be worn ... A man's skull may be converted into a lime pot for his widow and his long bones into lime spatulas (Barley 1997: 104).

deceased, the bereaved's relationship to the person takes precedence over accessing the body for organs. Without the families' permission (or more accurately, "lack of objection") procedures such as autopsies and dissection, are considered a violation to the body, and therefore a violation to the person. Regardless of quasi-legal rights of the body, or the way that the body will be ultimately disposed of,⁵⁹ to the bereaved it is "their person." For the relatives, because the dead body signifies the person once known, and because their past existence is tied up with their lives, it is the next-of-kin who decides what happens to the body (Kass 1992). Before the removal of organs, for example, a lack of objection must be ascertained because:

The common law properly mandates the body of the deceased to next of kin, in order to perform last rites, to mourn together in the presence of the remains, to say ceremonial farewell, and to mark simultaneously the connection to and the final separation from familial flesh (1992: 74).

Tension may be created in cadaveric donation because, on the one hand, the dead body may be viewed as a "means to an end" by the medical profession. That is, it is an anonymous body from which organs can be sourced or post-mortem research conducted. This is not to suggest this is a view all health professionals share. Lynch (1990: 1016) reported medical professionals' statements regarding organ donation:

I wouldn't want my child's dead body mutilated like that.

I am very ambivalent about being an organ donor, given the rough handling of the cadaver I see in practice.

I am anxious about the donor's family – do these people know what removal of all-usable organs and long bones entails?

The effect of the health professionals' knowledge about the process of organ retrieval may lead to ambivalence and personal beliefs, not necessarily entirely supportive of organ transplantation. Lynch suggests that, "To be professional ... is to be accustomed, if not inured, to the ambivalence experienced ...[to develop] 'detached concern'" (Lynch 1990:

⁵⁹ As regards disposal of the body, families that are planning a burial, are more likely to stress the integrity of the body and to have the person buried *whole*. Families intending a cremation, on the other hand, are found to be more likely to agree to donation (BACCN/UKTCA 1995: 19). Interestingly, from the 1950's onwards, cremation rose in popularity: in 1995 71% of families planned a cremation compared to only 1% in 1900 (Brierley, Religious Trends 01/00: 4.8). This may be indicative of a watershed in societies view of the dead body. Although further research is required to pinpoint why this change has occurred it is likely that a combination of the increasing expense of burial and a decrease in the influence of religion may be significant.

1016).⁶⁰ Yet, not all of the health professionals in the aforementioned studies have become “desensitised,” and may still be uneasy about organ retrieval, despite their knowledge of the procedures and benefit to another patient.

(RE)DEFINING DEATH

Change in the Visibility of Death

Transplanting organs is not just a surgical procedure involving the taking and integrating of an organ from one person into another. Rather, organs can carry with them a degree of symbolic and emotional significance, which can affect all those involved in donation. Moreover, the procurement of organs is not only contingent on how we perceive the gift being given, but rests on the condition of the donation act. Specifically, organ donation depends on individuals being able to consider what will happen to their bodies after death. By signing a donor card they have, in a sense, confronted their own mortality and eventual demise as a foreseeable event. Psychologically, organ transplantation forces us as individuals, to confront the meaning and eventual reality of death, a denial of which can have a negative effect on donation (Robbins 1990). Freud once observed that:

Our own death is indeed unimaginable and whenever we make that attempt to imagine it we can perceive that we really survive as spectators. Hence ... at bottom no one believes in his death, or to put the same thing in another way, in the unconscious every one of us is convinced of his own immortality (Freud [1925]: 304).

Some have taken Freud’s proposition further, arguing most Western societies are “death denying” and death is a “taboo topic.” Ariès (1974) in his seminal work spanning almost three decades, argued that the modern epoch is hallmarked by a fear of death, the dying hidden behind hospital walls and banished to the margins of social life. By documenting the slow, almost imperceptible changes in social rituals accompanying death over the past thousand years, Ariès observed that in the middle of the nineteenth century a “complete reversal of customs” occurred (1974: 562). Due to advances in medical therapies, the dying were removed to the sanitised place of the hospital where, not only could they be cared for, but also the new indecency of death could be concealed. Death, it is argued, has

⁶⁰ “Detached concern” or “clinical detachment” is not only a desired individual disposition but a process that can be historically traced to the beginnings of anatomical dissection. Moreover, the “ability to regard the human corpse as an object of close physical study represents a cultural detachment of no small dimension” (Richardson 1988: 31). No small wonder then that some health professionals find it a difficult stance to obtain and maintain.

become invisible through the rejection and elimination of ceremony, ritual and public mourning:

Once, there were codes for all occasions, codes for revealing to others feelings that were generally unexpressed, codes for courting, for giving birth, for dying, for consoling the bereaved. These codes no longer exist. They disappeared in the late nineteenth and twentieth centuries (Ariès 1974: 579).

For example, the once traditional ritual of the “wake,” keeping the body in the home for a few days preceding the funeral has become rare. Shilling (1993: 189) states that, “when an individual dies it is likely that she or he will be isolated from families and friends and subjected to the professional control of medical discourse and practical expertise. Rather than being an open, communal event death is now sequestered to the medical expert.” Data shows that over 70% of people in Britain will die in a hospital or similar setting (Mulkay and Ernest 1991: 173). Though there may be a growing demand for a representation of death, from war documentaries, to violent movies, to a hospital casualty ward, this can be considered an “anaesthetised knowledge” of death (Shilling 1993: 190). It isn’t an aim of this study to solve the debate of whether societies are death denying or not. It is how, and in what way, the conditions of death may affect organ donation. Yet, it does seem difficult to prove conclusively that, in the past, death was more visible and endemic, and therefore not as feared as it is now (Seale 1998). To all intents and purposes, it would appear the very existence of organ donation in the UK demonstrates there are a significant number of individuals willing to consider what happens to their bodies after death.

Brain Stem Death

Important changes have occurred over the last hundred years, not only with what can be done and what is done to dead bodies, but regarding death itself. One of the most significant changes is the shift from a traditional conception of death by cessation of heartbeat, to one where irreversible damage to the brain, a condition known as brain stem death,⁶¹ has been introduced. Before the concept of brain stem death was introduced, death was diagnosed by traditional cardio-pulmonary causes where cessation of heartbeat indicated the person had died. Pernick (1988: 17) wrote, “[O]nce upon a time, long before modern machinery, everyone agreed that death occurred when your heartbeat and breathing stopped.” This is no longer the case, and the paradox is that accompanying the

advancement of scientific and technological precision of defining death, come doubts about its diagnosis. As Giacomini (1997: 1478) argues, brain stem death was not solely a clinical definition, but a socially constructed one:

Brain-dead bodies had to be created, recognised, and defined in the development of brain stem death criteria: brain stem death was socially as well as clinically constructed. The 1968 definition did not produce a more “accurate” description of death so much as mark new delineations between the living and the dead.

Appearance of the Dead Body

As outlined in previous chapters, the appearance of brain stem dead individuals is far different from someone who has died from cardio-pulmonary causes. Colour appears normal, the body may still be warm, and the heart continues to beat, albeit with assistance. In Sque and Payne’s study of 16 donor families, they found that for some participants (though not shown how many) there was a “realisation of death,” when the next-of-kin was declared dead, prior to the clinical confirmation of death:

Then I looked in her eyes and her eyes were dead, there was no life in them whatsoever and that’s what made me decide ... completely cold, fish eyes, she had no life, no sparkle in her eyes and having seen that, that’s what made me think she was dead (Donor respondent, Sque and Payne 1996: 1362).

Despite acceptance that death was imminent, an actual confirmation of brain stem death was not uncontroversial, however, and caused some relatives concern:

I think that’s the worst, the hardest bit is accepting that they have gone, when he just looks as if he’s asleep and going to wake up and say, “where’s the coffee?” I think that’s the worst bit, just seeing them laying there but still warm and looking as if he was asleep (Donor respondent, Sque and Payne 1996: 1362).

Public Ambivalence

Corroborating evidence for the claim the public may be ambivalent about brain stem death (BSD) has been found in both qualitative and quantitative studies of families’ experiences of an organ donation request (Fulton 1987, Dejong *et al.* 1998). Throughout history, distrust of the medical profession and ambivalence about the diagnosis of death have been found, and accounts can be found as far back as 1740, when it was suggested by Jean-Jacques Winslow that, “putrefaction was [death’s] only sure sign” (quoted in Lamb 1985:

⁶¹ The term “brain stem death” has recently come to be preferred as this acknowledges that there is still brain activity going on, albeit superficially. See “A Code of Practice for the Diagnosis of Brain Stem Death” March 1998, DoH which replaces

51). During the eighteenth to twentieth century, as a result of new technologies, especially artificial resuscitation, which demonstrated individuals previously thought dead could now be revived, came an increasing uncertainty in the diagnosis of death. Though this was ended by an unprecedented enthusiasm and lay deference to medicine, this was an “historical aberration ... Lay mistrust of doctor’s definitions has been the historical rule rather than the exception, though such mistrust only periodically caused great alarm” (Pernick 1988: 61). The subsequent public disquiet and drop in donation rates in the 1980s, following the notorious BBC documentary *Panorama*, shown on Monday 13 October 1980, which suggested individuals had recovered from brain stem death, attests to the fine line physicians tread when dealing in the area of death.⁶² The medical community is aware of the difficulties brain stem death causes, however. In informal discussions with health professionals, one told me how:

The public still has a problem with pink ventilated bodies ... they may understand what’s being said but the fact is that they do not look like a normal corpse. I don’t think that there would be half the refusals ... they perceive them as still being alive ... I think you know... organ donation from a conventional corpse. If we could do it. Take the organs two or three days later I think we would halve the refusal rate.

Medical Ambivalence

Yet what of the medical profession response to brain stem death? Is it that they are immune to the same doubts and uncertainties as some members of the public? Does such a tight dichotomy of medical objectivity and lay subjectivity exist? If we consider that, in many respects, the medical personnel are instructed to treat these patients as if still alive, with life functions continually monitored, then it is unremarkable to find researchers such as Younger (1990) identifying ambivalence in those health professionals, working with “heart-beating” [brain stem dead] donors. He found considerable health professional misunderstandings about the correct clinical and legal criterion for determining death, suggesting that the medical professionals involved are not dealing with death, in an “objective” manner. The concept of BSD, therefore, challenges both public and medical professionals’ understanding of death, and can pose an obstacle to donation. It takes public trust in the medical professional to the extreme, and may simultaneously stretch health professionals’ belief in the diagnostic capacity of medicine.

the previous Working Party Paper (February 1983). Thanks to Magi Sque for pointing this out.

⁶² Lamb suggests that in cases that have supposedly “recovered” from brain stem death the criteria for diagnosing the condition had not been met (for a fuller discussion see Lamb (1985: 66).

Modern day Resistance: Denmark and Japan

Brain stem death is not without critics, medical, ethical and lay alike. One bioethicist insists that, “[Brain dead bodies] appear to be alive because in fact they are alive” (quoted in Lock and Honde 1990: 103). This is a debate not likely to subside. For example, authors employing Pernick’s work agree with his premise that, “neither the controversy nor the process has changed substantially over the past 250 years ... in searching for death, or life, in patients,” and added that, “our testing is no better able than that of our predecessors to measure that which is not solely a medical diagnosis” (Powner, Ackermann and Grenvick 2000: 1219). Although the criterion for brain stem death achieved eventual world-wide recognition, it met with some resistance both soon after it was introduced, and later from countries such as Denmark and Japan (Ohnuki-Tierney 1994).

Denmark was one of the last countries in Western Europe to accept the irreversible loss of all brain functions as a criterion for death. Rix (1990a) suggests this is due to the importance the Danish government places on public consensus and, “that a public debate must precede legislation on the brain stem death criterion” (1990a: 232).⁶³ A report by the Danish Council of Ethics (DCE) asserted that, “any change in the criterion of death is an event of such significance that it should not be permitted without a major public debate on the ethical questions involved” (Rix 1990b: 5). It was argued that, first, this ensures a general basic knowledge in the population and second, all advantages and disadvantages have been presented. In 1990, the DCE rejected the medical criteria for brain stem death as death, and argued for a concept of death that is, “the everyday experience of death common to individuals of a particular culture” (Rix 1990b: 6).

Proponents of BSD, were quick to reply (Lamb 1990). Inherent in the DCE’s decision, Lamb argues (1990), is an untenable contradiction, between cardiac transplantation and cardiac death. By definition, the two cannot be reconciled, although the DCE attempts to do so by, “offering a curious notion of a “death process” which begins with brain stem death and ends with the cessation of cardio-respiratory function, in the middle of which cardiac transplantation is permissible” (Lamb 1990: 8). In other words, it accepted BSD as the irreversible onset of death, suggesting it was the beginning of the death process and cessation of cardio-pulmonary activity the end, with cardiac transplantation occurring somewhere in-between. Without going into further detail regarding this debate (see,

⁶³The importance of public confidence in brain stem death cannot be underestimated in Denmark. This is a country that since the nineteenth century installed electric bells in their mortuaries in case someone who was not actually dead could call for help (Rix 1990: 235). Given that there were uncertainties in the past regarding the diagnosis of death through cessation of heart beat, it is not surprising that a criterion of death based on brain activity would raise new issues.

however, *Journal of Medical Ethics* 1990 for further discussion) it is sufficient to note that the DCE attempts to reconcile the “everyday perception” of death as the cessation of heart beat with a brain oriented one ended in confusion. The Danish government eventually accepted brain stem death, and implemented presumed consent legislation.

As in Denmark, Japan also had the technology and knowledge of organ transplants available, but because BSD had not been widely accepted, transplants were limited to living donors only. In 1990, for example, nearly 2000 heart transplants took place in the States, whereas not one occurred in Japan (Lock 1995: 5). Japan now recognises brain stem death (the new law was passed on October 16 1997) and cadaveric donation is both possible and legal in that country. However, as Lock and Honde (1990) argued, before this change to the status quo could occur, as in Denmark, emphasis was placed on public consensus. For the last twenty-five years debates raged in Japan, with public opinion regularly monitored. In the media, the controversial nature of the scientific evidence presented meant that the issue revolved around the establishment of clear, valid criteria, the same debate regarding brain stem death that dominated Western literature, thirty years previously. The exception was that, in Japan, it mainly occurred in the public sphere.

Though similar debates may have occurred in both Japan and the West regarding the scientific criteria for brain stem death, culturally in Japan there were significant differences regarding the relationship between body and person.⁶⁴ Lock and Honde (1990) discuss how cultures that have a strong emphasis on Cartesian Dualism, and therefore a distinct mind/body split, are more likely to accept the criteria for BSD (1990: 109). In contrast, in Japanese culture, there is a widespread belief that the body and soul are integrated, the word *kokoro* is written with the character for the “heart” referring to the “spirit” (Lock and Honde 1990: 110). Hence, the individual cannot die until the heart has stopped, similar to the traditional Western conception of death that equates death with the cessation of heartbeat. Further, according to Buddhist beliefs, if an individual is not to be reborn it will be known within seven days (Klass 1996: 62). However, if the deceased is to be reborn it will be known in forty nine, thus “for the first forty-nine days after death the spirit of the deceased remains in this world. It would be highly inappropriate and very troubling to many families to know that they had allowed parts of the body of a dead relative to be removed” (Lock and Honde 1990: 110).⁶⁵ Even those who do not believe in Buddhism *per*

⁶⁴ This is not to imply that Japan is not as “modern” as the West, or that as a nation it is held back by a “culture of tradition.” It is likely that a number of factors are at work (for example, Lock suggests that the “politics and power relations among the professions, and between the medical world and the public, are implicated” 1995: 5).

⁶⁵ Both Shinto and Confucian derived religions also prohibit any interference with the dead body. The former is

se, still respect the Buddhist rituals pertaining to the belief that it takes the deceased relative thirty five or fifty years to, “be at one” with the community of spirits and ancestors (Klass 1996: 59). This involves the carrying out of rituals, such as placing a photograph of the deceased in a *butsudan* (the family altar usually in the eldest son’s home). There, relatives “talk” with the deceased and food is, on occasion, offered (Lock 1995: 19). In general, interactions in front of the *butsudan* tend to continue the relationship whilst the deceased was living.⁶⁶ Although the deceased is biologically dead, they are very much socially “alive,” or to be more precise, continue to have a social presence for the relatives.

So, although Japan has legally accepted brain stem death, it has made little difference to medical practice regarding organ transplants. However, Japan is not alone in placing importance on the continuing social presence of the deceased, religious or otherwise.

POST-DONATION - SOCIAL PRESENCE AND BIOLOGICAL DEATH

As the discussion of Japan attests to, because a person is biologically dead, this does not necessarily mean that they continue to cease existing socially. Two classic ethnographies, (Glaser and Strauss 1965, Sudnow 1967) carried out in the United States, examined dying and death in settings such as the hospital and the residential home. Goffman’s concept of a “non-person” defined as, “standard categories of persons who are sometimes treated in their presence as if they were not there” (quoted in Mulkay and Ernst 1991: 173) was employed as a basis for social death. This is not to suggest that medical treatment was withheld from those considered “socially dead,” rather they did not exist as “active, individual agents” (Mulkay and Ernst 1991: 175). Both Glaser and Strauss (1965) and Sudnow (1967) highlight that, within the hospital, social death can occur in conjunction with the realisation the patient is clinically dying.⁶⁷ This can vary; for example, the nursing staff may treat the patient as socially dead, whereas the relatives do not. However, Glaser and Strauss (1965) and Sudnow (1967) assumed, along with the medical professionals in their study, that once biological death occurred, so then did social death (Mulkay and Ernst 1991).

concerned with pollution and ritualises any contact with the corpse. The latter teaches respect for the dead body including its care and treatment (Lock 1995: 23).

⁶⁶ Klass relates an amusing story, which emphasises how the living bonds, with a “nearly deaf old man” continue, relatively unchanged after death. “Smith was away when the old man died; when Smith returned, he came to the man’s house and asked if he could burn incense at the family altar. The wife of the house was pleased. She put one of the cakes Smith had brought on a dish and took it to the altar. She knelt and said loudly, “Grandfather, Mr. Smith is here” (Klass 1996: 66).

⁶⁷ Sudnow (1967) also found those groups of people; perceived to have low social worth were more likely to be treated as socially dead by health care staff. More alarmingly, however, was the fact that social death then became a predictor for biological death. Timmerman (April 1997) demonstrates that the legal mechanisms invoked in attempts to stop such health rationing based on social worth paradoxically reinforced such death inequalities.

The termination of social existence is usually linked to the biological end of life. However, as Mulkay and Ernst demonstrate social and biological death are not necessarily identical. Although more research is required, social death may not occur until sometime after biological death, if at all. Klass, Silverman and Nickman (1996) also suggest the bereaved continue to have a “relationship” with the deceased. The deceased arguably still plays a part in the bereaved’s life, “... as a role model, as giving guidance in specific situations, as clarifying the values of the survivor, and as a valued part of the survivor’s biography” (quoted in Walter 1996b: 11). Walter places too much emphasis on the effect that the deceased continues to play in the life of the bereaved, yet his arguments are reiterated by research that Klass *et al.* quote. In the first few years after a spouse’s death, the bereaved still maintain an active connection to the deceased, dreaming and talking to them, and occasionally feeling “watched” by them. In other words, the relationship continues, despite the absence of the other’s physical, embodied presence.

Klass *et al.* (1996) suggest the standard psychological view of the bereavement process, i.e. “the purpose of grief is to sever the bonds with the deceased in order to free the survivor to make new attachments,” is misguided (Klass, Silverman and Nickman 1996: 3). Authors such as Walter (1996b) question the “clinical lore” of bereavement counselling, which is based on the principle that the purpose of grief is to sever ties with the deceased.⁶⁸ Rather, as Walter argues, it is entirely up to the individual whether or not they go on to sever ties and form new attachments. It is only a twentieth century phenomenon that deemed “maintaining an ongoing attachment to the deceased was considered symptomatic of a pathology” (1996: 5). The standard view of detachment arose due to a tendency of viewing people as autonomous, individuated actors bereft of interdependence:

Independence rather than interdependence, is prized ... There is little place in this model for any idea of individuals as interdependent and living in a web of relationships. In this modern view humans are understood to have a limited amount of energy for any one type of relationship. To have a new relationship we need to give up the old one (Klass, Silverman and Nickman 1996: 15).

In light of this, the purpose of grief may be not one of detachment, but of “resolution,” of “finding an appropriate place for the dead” (Walter 1996b: 12). The process of gaining this

⁶⁸ As Walter points out, it is interesting that early work conducted in the area of grief, such as that by Bowlby (1991) never actually posited that the purpose of grief is to sever ties, rather as Bowlby suggests himself the aim was to “counter those biases ... [that] suppose a normal healthy person can and should get over a bereavement not only fairly rapidly but also completely” (Bowlby 1991: 8).

“resolution” is through internal dialogues with the deceased and external dialogues with others known to them. This helps to “clarify thoughts, deal with unfinished business and emergent relationships, and prepare for the future” (quoted in Walter 1996b: 13).⁶⁹ It is not the case that the bereaved continue to pathologically live in the past (though one might expect this to happen in a minority of cases), rather the existence of past social bonds informs present and future behaviour.⁷⁰ The deceased is physically gone, but socially present, “[P]lay, smile, think of me, pray for me. Let my name be ever the household word it always was” (Walter 1996b: 9). Although requiring further research, it is likely there will be a correlation between the nature, intensity and length of the living relationship with the deceased’s continuing social presence. For example, in the case of a stillborn baby or a child death, continuing social identity may be based on an imagined future relationship (Hallam, Hockey and Howarth 1999: 14). The parallels with the Japanese bereaved hardly need to be drawn out further, except perhaps to note that religious instruction or cultural belief may not necessarily inform this continuing social presence.

Social Death/Existence and Organ Transplantation

As members of society we live in a “a web of social relationships,” and in part, the basis of such relationships is due to the fact, we are embodied. To interact with others, is dependent on having a body to interact with. To be embodied is to present “self in body,” and our personal identity and social existence is inextricably inter-linked with our corporeality. However, it is also possible for these three elements to come apart at death. Similar to a Dualist version of personal and bodily identity, after death, the deceased’s personal identity can socially persist in the previous world of the bereaved. In other words, social actors can continue to exist without a bodily referent. The question is what effect does this have on organ donation?

If donation does occur, the continuing social residues of the deceased may lead to a desire on the donor families’ part to try and communicate with the recipient; this coincides the person with the body again, as is normally the case of embodiment. Alternatively, for the bereaved this is a time when their thoughts turn to their deceased relative. Therefore, it is likely their thoughts will also turn to the recipient who, in a sense, is now a part of the continuing social existence of their loved one. The recipient may now play a part in the

⁶⁹ If the bereaved prefer talking to people who knew the deceased, then the implications for bereavement counselling, are as Walter argues that the “talking about feelings to a stranger is a rather poor, if much appreciated, second best when there is no-one available with whom to talk” (1996b: 19).

⁷⁰ Walter, in a similar analysis, views the dialogue of grief as a way in which individuals in late modernity make sense of their own, and the deceased’s life. In this interpretation, it is more about the construction of identity based on previous social bonds with the deceased (Walter 1996b: 20).

continuing “biography” (as Walter terms it) of the deceased. This may explain why, for some donor families, it is important for them to have some contact with the recipient, so that they can reaffirm the biography of the deceased.

Relatives of brain stem dead individuals make the decision to donate or not through knowledge of the deceased’s wishes. However, indirectly it is also possible for them to frame it without knowing whether this was their relative’s wish. Rather by employing their knowledge of the deceased the family can suggest that “well although s/he did not express their wishes regarding donation, from what we know of them whilst they were alive, that’s what s/he (the deceased) would have wanted.” In this interpretation, the family’s decision making is based on the past actions and behaviour of the deceased. Paradoxically, if they decide to donate, it is also possible for the family to re-interpret the past actions of the deceased whilst alive, on the basis of the donation decision. Organ donation can then offer the relatives the opportunity to remember the donor in a more favourable light, aiding them in their grief. As I was told in a discussion with a health professional, some donors “got their tickets to heaven,” not because of anything the donor did whilst alive, but because something worthwhile came out of their death:

Those who haven’t made an expression to the relatives by having a donor card or I’d like to donate, the attitude largely is that “he [sic] was a good person, he would have liked to help someone, he used to go down in the morning and put the kettle on, that sort of thing. A general attitude to life.” The other thing that comes to mind as well is that mm... in cases where the person has been a bit of a “monkey.” Men, young men who have been in trouble a bit. Right? You know they’ve died in a stolen car whatever. The ability to donate then makes them “go to the angels”. Because instead of being remembered as a bad boy who having nicked a car and crashed it into the wall and died and injured his friends, he’s remembered in the family as the last thing he did was donate and help somebody else.

The above quote demonstrates how the internal representation of the deceased by the family highlights the altruistic nature of the deceased, and plays down the actualities of their death. Thus, although the continuing social presence of the deceased may correspond with the actual living characteristics of a person concerned, in other contexts the family can “orchestrate” memories of the deceased through the act of donation. Remembering the deceased as a donor, arguably aids them in their grief.

SUMMARY

In our day to day living, “bodies” are a taken-for-granted phenomenon. It is not until we are asked to give parts of them away, that we realise how much we are “attached” (in both senses of the word) to them. Transplanting organs from one individual to another involves a host of social and cultural issues that prove to be illuminating for those interested in the sociology of the body. The body, both living and dead, and its perceived relationship to the intangible facets of personhood, affect the decision to donate organs in a myriad of ways, not only at the individual level, but also at the macro- level of a country’s acceptance of the procedure. Throughout this chapter, emphasis was placed on the cultural aspects of bodies, yet this is not to argue the existence of a simple, causal relationship between cultural resistance and organ donation. The more modest claim is that, in *some* cases, belief systems integrating personal and corporeal identity cause concern for donor and recipient. Taken as such, this is more about the experiences of donor families and recipients, and what this can say to sociologists about a person’s lived experience of their body.

For example, the discussion has shown beliefs about embodiment/disembodiment and dualism/monism are more complex than initially considered. The discussion of the social construction of organs highlighted the implicit existence of a monistic approach to embodiment. In part, this may stem from an inherited cultural tradition, however, the persistence of such beliefs can be explained, - the experience of self is bodily incorporated. To appear as a person is to give evidence of a “self in a body.” This may have contradictory effects on organ donation. Evidence suggests that, donor families may donate in the belief they are gaining for the deceased a “physical immortality,” the donation of organs suggests organs carry vestiges of the person in them, and will continue to survive in a body of other. However, it is also not unreasonable to suppose that because of the integral relationship between body and identity, some families may not want to give parts of their relative to an anonymous another. In their view, the personification of the deceased’s body means they cannot consider the idea that the body would be opened up and organs removed. A monist view of the body leads to the restriction of certain organs considered more integral and important to ideas of personhood, such as the eyes and the heart. Therefore, three outcomes can be explained from an integrated view of person/body monism: restriction of organs, bodily immortality and refusal to donate, all hypotheses require further empirical verification, however.

Not only do beliefs about the body and its parts influence whether or not they are donated, but the environment under which they are donated can also have profound effects. Brain

stem death, blurs the presumed dichotomy between medical, objective diagnosis and public, subjective emotion - health professionals are not immune to doubts and debates about BSD and are susceptible to the same emotional “baggage” regarding death, and dead bodies, as the public are. Brain stem death, has not only caused debates regarding the scientific criteria of death, but also wider social and cultural ambivalence pertaining to the apparent “breathing corpse.” This is not just a breathing corpse, but a breathing person, as monist beliefs regarding embodiment can persist right up to the moment of death. Then, beyond the biological lies the social.

The idea that a dead person can continue in the social world previously occupied is neither an unusual nor a controversial concept, though its application to organ donation is unique. Although medicine declares life has ended, the person does not just cease to exist. Akin to a dualist version of person/body, which emphasises the persistence of person after death, here an amendment is made; the person can continue to socially exist, despite no longer being embodied. This is not an atheist way of denying death, but a ubiquitous phenomenon, which questions whether bonds with the deceased are broken at death. I argued that the strength and power of previous social relationships keep the deceased present in their previous social world, regardless of religious instruction. How the person can continue to be socially present for others, without biological referent, is highlighted in the idiom to be with someone “in spirit but not in flesh.” A person who dies is not simply forgotten. They continue not only to be remembered and to influence present and possible future behaviour of others as statements such as “it’s what s/he would have wanted” imply. Moreover, by donating the family can adjust their memories of the deceased; through focusing on the donation act itself allows the social presence of the deceased to continue in a more favourable light. Social presence can therefore transcend the “spatio-temporal existence of bodies” (Lamb 1985: 86). Questions remain, however, for how long and in what form is a person remembered? Until their generation dies? Does the intensity, length and nature of the previous relationship affect whether a person is remembered or not? These are questions that do not have answers, although work such as Klass *et al.* (1996) and Mulkay and Ernest (1991) are making significant inroads into what the social repercussions of death are.

Introduction

In this chapter, my aim is to operationalise some of the main theoretical concepts suggested in Chapters 4 and 5, and utilise the contributions and limitations of previous studies into donor and non-donor families outlined in Chapter 3. The aim of this research, generated from previous discussion, is to assess the wider social values of altruism, the body and death in wider society. Whether and how these relate to the specific context of organ donation and transplantation, taking into account factors such as the impact of personal, familial and health professional support shall also be examined. First, an examination shall be given to issues of sample size, how the families were to be contacted and justification of methods. Next, since the interviews were carried out with bereaved family members, and utilised NHS resources, an overview of gaining ethical approval is offered. Finally, an outline of the interview schedule is presented (see Appendix A) explaining the link to theoretical concepts and findings given in previous chapters.

Why semi-structured interviews?

From the outset of the study, my intention was to carry out interviews with donor and non-donor families. Semi-structured interviews were chosen as the desired research tool because they fulfilled the requirements of the research, that is, to examine donor and non-donor families' experiences in an in-depth manner. More structured methods, such as self-completion questionnaires, were initially considered as a research tool, and might have been less threatening and easier for the participating families to approach (for example, they do not involve a face-to-face interaction). Previous quantitative studies in the area show a high response rate - 84% for donor families and 58% rate for non-donors (Dejong *et al.* 1998: 14). Batten (1990) also reported a 61% response rate to her postal questionnaires to donor families. It was eventually decided, due to the requirements of the study and the nature of information being sought, this would best be collected with the use of semi-structured interviews (Rubin and Rubin 1995, De Vaus 1996, Robson 1997).

Semi-structured interviews were considered particularly desirable for several reasons. First, semi-structured interviews avoid the interviewee having to answer potentially distressing questions about the donation decision. That is, interviewees are given the opportunity to recount their version of events, with only minimal prompting from the interviewer. Second, semi-structured interviewing is a research method that allows the definition of topics in advance; due to the theoretical investigation of altruism, gifting and

the body, along with the results of studies reported elsewhere, I wanted to test preconceived concepts. This is not to suggest these concepts were to be rigidly imposed on the study, rather the flexibility of this qualitative method permits concepts and hypotheses to be tested, whilst simultaneously, allowing sensitivity to the emergence of new themes as respondents were given the opportunity to recount their version of events (Dey 1993, Miles and Huberman 1994, Lofland and Lofland 1995, Mason 1997). Themes identified from the previous literature and research, which were used during the interviews and subsequent analysis, were:

1. Demographics of the families (respondent and deceased).
2. Perceptions of health professional support.
3. Beliefs about death (including brain stem death).
4. Beliefs about the body.
5. Family dynamics.
6. Views about the procurement process.
7. Reasons for donation or non-donation.
8. Beliefs about organ transplantation (including retrospective views of experiences).

Because I was asking questions around these themes in the interviews, I expected the respondents' answers to be subsumed under at least one of them. The procedure followed differed somewhat from this expectation, as will be discussed below. I transcribed each interview verbatim and the text was imported into a qualitative computer package that would aid the management of data (QSR NUD*IST 4 - an acronym for Non-numerical Unstructured Data by Indexing Searching and Theorising - was chosen). The qualitative computer package NUD*IST was viewed as desirable because it allows areas of interest to be turned into thematic codes (or "nodes") during the preliminary stages of analysis. At a later stage, it also offers the researcher an ability to "think aloud" when engaging with the data on-screen and change coding if needed.

Each thematic code (themes 1-8 above) was assigned "child nodes"; a sub-set of a particular thematic code. For example, underneath "*beliefs about the body*" (3) a sub-node could be created called "*post-mortem concerns*" (3:1). Respondents' answers generally fell into one of the previously identified thematic codes, and were easily developed into straightforward sub-nodes, which later gained increasing complexity. To give such an example, "*family dynamics*" (5) had a sub-node of (5:4) "*communication between members.*" This was eventually broken down again after further interviews into "*positive*

reactions" (5:4:2) and "*negative reactions*" (5:4:3) depending on a respondent's view about their family reactions to the organ donation request.

As the interviews progressed, new and unanticipated data emerged, which required the questioning and coding to change. For instance, the phenomenon of social death was an unexpected theme that arose during the first few interviews. This could have been sub-coded under "*beliefs about death*" (3). Yet, because I was unsure how complex an issue this was, or might become, I chose to assign it a thematic code of its own, "*social death*" (9). Indeed, sub-nodes did eventually transpire such as, "*timing of social death*" (9:2). Then, making and justifying such coding decisions required a great deal of reflection, engagement and scrutinising of the data throughout the analysis.

When the interviewing was finished, NUD*IST allowed the coded responses to be accessed and compared. For example, "were respondents who restricted organs also more likely to be against presumed consent?" And, "was there was any relationship between social death and health professional communication?" NUD*IST therefore, did not analyse the data or identify relationships within it. Rather, it was a useful computerised data retrieval tool, which allowed the qualitative data to be systematically organised and retrieved. Further discussion regarding the inter-linkage between thematic codes and questions during the interview is given under "Identified areas of Interest: Development of Interview Schedule."

RECRUITMENT

After deciding on the research tool, a sample size of thirty families (fifteen donor and fifteen non-donor families) was chosen. First, the parameters of the study were informed by similar fieldwork (i.e. Fulton *et al.* interviewed 14 donor families) and, second, because of constraints of time and funding, there were not enough resources available to conduct a larger study.

Decisions then had to be made about how to gain access to the sample. There were two potential avenues that could be explored. First, support groups such as B.O.D.Y. (British Organ Donation Society). Yet this was the least desirable means of access for two reasons. First, it would not give access to non-donor families. Second, in approaching donor families through such groups, the sample could potentially be skewed, as it is only those families who would be seeking additional support being interviewed. I thought this likely to lead to only a partial view of organ donation. Thus, I considered it essential the medical

profession supported this study so the findings were able to present a balanced point of view, and to be generalisable to donor families as a whole.

So, permission was obtained from the president of the Scottish Intensive Care Society (S. I. C. S.) to use information from their database for the purposes of this research. In Scotland, for the last two years, a record has been kept of acceptance and refusal of donation, alongside next-of-kin's names, addresses, and unit where donation was requested. Data for the region where the research was to be conducted was identified by the director of the database, and then forwarded to a named health professional at the hospital involved in the first phase of recruitment. The database began two years ago, and a sample size of fifteen donor and fifteen non-donor families was initially thought viable, even taking into account that the non-donor family pool was significantly smaller, that is, only 30% of families approached refuse an organ donation request (Gore *et al.* 1991). No matching of deceased characteristics was made because the size of the sample was too small, and variables that are controlled for cannot be tested to assess whether they have an impact on the decision to donate or not. Further, as no other similar study has been conducted in Scotland, the aim of this research was primarily exploratory and therefore all other factors, including age of the deceased, was considered potentially significant.

GAINING ETHICAL APPROVAL

However, prior to any contact with the families, ethical approval had to be sought from the appropriate NHS trusts. Careful consideration was given to ethical issues, as the sensitive nature of the questions meant that interviews could potentially trigger emotional distress for bereaved relatives. In addition, the intention was that the sample would be recruited through NHS institutions and staff, therefore the research had to receive the approval of the local ethics committee. Gaining full ethical approval for all three NHS trusts taking part in the study took approximately 14 months and was not fully achieved until February 2001. In general, ethics committees had three main concerns needing to be addressed: i) anonymity, ii) confidentiality and iii) avoiding distress to the respondent.

Anonymity

Due to the concerns of the ethic committees regarding access to confidential NHS medical records, the details of the donor and non-donor families were secured by named health professionals at the three main hospitals involved in the study. The only information I had access to was provided solely by the respondents themselves, after they had agreed to take part. Though the researcher's status as an "outsider" raised issues about access to

information about the sample, this position was thought advantageous for two reasons. First, as an outsider to organ donation procedures any taken-for-granted assumptions others might have within the area are avoided. Second, respondents may feel more at ease discussing their experience of the organ donation request with someone not involved with organ procurement, and who may be perceived to be “neutral” in their views regarding organ donation.⁷¹

Confidentiality

The respondents were advised in the Patient Information Sheet (see Appendix B) that if they decided to take part the interviews would be taped. Permission to tape, in order to gain an accurate recollection of the interview, was verified prior to interviewing, and in case the respondent objected to this, I was prepared to take hand written notes.⁷² All participants were given an unconditional statement of confidentiality and anonymity. In response to recommendations made by the ethics committee, during analysis this confidentiality was maintained by: i) only the researcher transcribing the interview, ii) the use of a code number on the transcript and thereafter, iii) destroying the master copy of names, codes and tapes after data collection and analysis. Respondents were assured pseudonyms would be used when referring to individuals in the final report, and care taken to avoid identification with any particular NHS institution.

Avoiding distress: In Recruitment and During the Interview

Of cardinal importance to the inquiry was to avoid, as much as possible, causing any emotional distress to the respondents. Potential distress could be caused in two ways. First, initial contact in introducing the study via the health professional’s letter of introduction, Patient Information Sheet and Consent Form (Appendix B).⁷³ In this study, respondents were asked prior to the interview about their reaction to the letter inviting participation in the study. Those that agreed (n=19) reported no adverse effects although this may not have been the case with those who declined participation/did not respond (n=32). Indeed one woman who refused to take part in the study wrote:

⁷¹ Doering (1996) acknowledges that being an interviewer, and a nurse and co-ordinator, may have inhibited the respondents’ expression of certain thoughts and feelings about the donor family experiences in her research.

⁷² In fact none objected to the taping of the interview.

⁷³ No copy of the health professional letter is attached – due to ethical considerations I did not see a final draft of the letter as it contained the families’ names and addresses.

I would prefer if I had no further communication from yourselves, it is a hard enough decision to make at the time and every time you contact me it makes me very disturbed indeed. I did what I thought was correct at my sons death and I am still trying to get to grips with the suddenness of it all and you keep reminding me with these awful questionnaires and it also just keeps researchers in a job to put another stastic [sic] on a computer.

This mother is obviously still very upset regarding the death of her son. This type of answer (though occurring only once) caused a high level of anxiety regarding the balance between gaining valuable information about organ donation, and causing people unnecessary distress. This turned out to be an isolated episode, and most respondents were pleased to relate their experiences. Indeed, other studies have demonstrated family members participating in similar research, “expressed an appreciation for the opportunity to share their experiences as well as the hope that they would ultimately benefit others” (Pelletier 1993: 153).⁷⁴

In this study, one respondent was unsure whether she was “what I was after,” as her family had approached the health professionals about donating. But she added, she “had no qualms about taking part or anything else like that” [Mrs M: 18].⁷⁵ Others were also initially undecided whether they wanted to take part and needed time to consider it further. Mr F eventually decided, “well, it’ll certainly not do any harm and if it helps somebody later in the same position as me, fair enough” [Mr F: 12-14]: a sentiment echoed by another respondent, “if what has happened can be of use to anyone else I think that’s a good thing” [Mrs K: 587-589]. Mr U, did not like the term “lack of objection” used in the health professional’s letter of introduction, however, as discussed with him, this is the current terminology stated in the 1961 Organ Transplant Act and the legally binding term to employ.

Because the interview was about the loss of a close family member there was always a chance, however small that this could trigger emotional distress. Several strategies were employed to minimise any potential for emotional upset. First, a sufficient passage of time was allowed between the relative’s death and an interview with the bereaved relative(s). From discussions with health professionals, members of the ethics boards, supervisors and personal experience of a close family bereavement, a period of at least six months after a donation request was finally selected (albeit acknowledging the fact that “no time may be a good time”). After careful consideration, the possibility of distortion from having to rely

⁷⁴ This finding was repeated in other research that found only *one* of 164 respondents terminated a telephone survey, carried out just 4 - 6 months after the donation request (Dejong *et al.* (1992).

on people's memories could be avoided, by careful study of repeated themes throughout the course of the fieldwork. During the interviews, issues did arise regarding the respondents' recollection of events. Some respondents were able to recall traumatic events with extreme precision and clarity. However, others had trouble remembering incidents and, in some accounts, there are gaps in knowledge about the organ donation process. In part, this is due to the length of time between events and the interview, and the shock and grief following the death of their relative.⁷⁶ This was alluded to several times, with responses such as, "it's all a bit of a blur," [Mr. F: 258] and, "it's like you're in a nightmare. It's as if it's not happening to you" [Mrs. K: 330], and "you go into a sort of dream" [Miss A: 260].

The second strategy used to avoid causing unnecessary distress, was to ask the health professionals involved in the study – intensive care unit staff, transplant co-ordinators and General Practitioners – to screen out potentially unsuitable participants.⁷⁷ Third, the respondents were advised in the Patient Information Sheet that another member of the family, or a friend, could be present to provide support during the interview, if so wished (see Appendix B). Fourth, I suggested to the relatives before the interview commencing that, if they felt it was becoming distressing, the questioning would be immediately terminated.⁷⁸ In the event of this occurring, I was told by health professionals that the respondent should be asked whether they would like their GP informed, in order to seek some form of further support. Alternatively, I would offer to put them in touch with a bereavement group such as CRUSE, or in the case of donor families, their transplant co-ordinator or an organ donation support group such as the British Organ Donor Society.

Respondents' Experience of the Interviews

The interviews usually took place in the respondents' own home at a time convenient to them. They lasted on average one to three hours, including periods at the beginning and end of the interview where general conversation created an amenable context for the generation or closure of discussion. Despite the intense and occasionally upsetting nature of the interview, none of the respondents reported or displayed any adverse effects.⁷⁹ Two

⁷⁵ The numbers indicate the position of the statement within the transcripts coded using QSR*NUDIST 4.

⁷⁶ Understandably the respondents interviewed after 3 years had more difficulty recalling events.

⁷⁷ One GP shared the researcher's concerns regarding a respondent who had agreed to participate. The consent form was not filled in correctly and after discussion with the GP it was agreed that the researcher would not approach this relative, rather the GP would contact her patient and discuss it with her further only informing me if she thought the research could go ahead. This subsequently did not occur.

⁷⁸ During the course of the fieldwork it was possible to avoid being "engulfed by the demands of the setting" (Lee 1993: 137) through taking periods of remission from the conduct and analysis of the interviews.

⁷⁹ I adjusted the nature of probes and prompts to the perceived level of distress exhibited by the respondent.

respondents stated they found the interview “enjoyable.” Mr. F, for example, said “well there’s one thing I’ll say is that, to be honest, it’s been like counselling which I’ve been too proud to do, eh I’ve enjoyed talking about it today” [Mr. F: 761]. The last donor family interview was terminated with the agreement of the respondent. Due to the respondent’s high level of distress (stemming from unresolved issues relating to donation) we agreed there was nothing to be gained by continuing with the questioning. Prior to the interview, the respondent suggested there was a possibility she might become upset, however, she said she was keen to relate her experiences (Mrs. G). She declined further support from her GP, but agreed to contact the transplant co-ordinator in order to discuss her concerns. She showed no further signs of distress and appeared relaxed. A few days later I followed up with a telephone call to ensure this continued to be the case. None of the other respondents showed levels of distress requiring G.P referral, with only one wishing further information regarding bereavement counselling.⁸⁰

Who contacted the families?

Due to ethical concerns regarding the sensitive nature of the research and the confidentiality of patient’s medical records, I did not directly contact any of the potential participants. Rather, the research was introduced in writing, to the families, either through the transplant co-ordinators or in the case of non-donor families, staff in the ICU.⁸¹ A letter from the health professionals introduced the research, and was accompanied with a Patient Information Sheet and Consent Form.

In the Patient Information Sheet respondents were informed their participation was entirely voluntary and confidential. Further, if they had any queries about the research they could contact the researcher, or either of two named health professionals (one acting as an independent advisor, not associated or involved with any part of the study, the other involved with the initial stage of recruitment). Due to the length of time that might have passed since the donation request, permission was also sought from the potential participants to approach their General Practitioner (see Appendix B). The researcher then informed the G.P of the families of their intention to take part in this study. The G.P was asked for a more recent up-date of families’ status, and whether they knew of any reasons why the relatives should not be approached. Only after transplant co-ordinators and the

⁸⁰ Mr F was the only respondent to accept a leaflet regarding further counselling, stating that “I don’t think I need support on the organ donating bit. Eh [crying] I just miss having half my life whipped away” [Mr F: 782-783].

⁸¹ The effect of this on the response rate is difficult to gauge. Although the introduction to the research by health professionals avoided ethical concerns about the researcher’s involvement in the preliminary stages of recruitment avoiding issues of confidentiality, it may have led to a perception by some respondents that I was affiliated with that particular NHS institution.

patient's G.P advised there were no contra-indications to participation, was the family then contacted by the researcher in order to arrange an interview at a time and place convenient to them. (For a schematic overview of the recruitment process please refer to the flow-chart in Appendix C).

Phase 1- East Scotland (July 2000)

During Phase 1 of recruitment nineteen letters of introduction were sent to donor families living in the East of Scotland by the transplant co-ordinator, July 2000. Given the restrictions on time, location, and ethical considerations (such as the health professionals' veto), this was a much smaller sample than desired. Of the initial nineteen contacted, nine people returned the consent form, with five agreeing to take part (26% agreement rate).

Phase 2 – North Scotland (February 2001)

In order to increase the sample size, it was decided to extend the time period of the study by a further year to 1997, and widen the location to include other regions the transplant co-ordinator covered. This involved gaining further ethical approval from the respective NHS trust, eventually approved in November 2000. Subsequently, a further seventeen letters were sent out to donor families January 2001 (thereby avoiding the festive period). Fourteen returned letters, with seven agreeing to take part (41% agreement rate) bringing the total of number of donor families to twelve. The higher response rate for Phase 2 may be due to the extension in time. An extra year may have made the donation decision, and indeed bereavement, less distressing for the respondents to discuss.

Phase 3 – West Coast (March 2001)

Because the desired sample size for donor families was fifteen, a decision was taken to extend the study yet again – this time to an area in the West of Scotland. Again, after ethical approval was gained for this area, ten letters were sent during March 2001. Six returned with three agreeing to participate – the desired sample size of fifteen interviews were therefore reached. In sum, of the 46 letters sent to donor families, 29 were returned, with 15 agreeing to take part (32% agreement rate). Nineteen donor respondents finally participated in the interviews, as some respondents also brought along spouses or siblings involved in the decision. This participation rate was lower than Sque and Payne's (1996) donor research (50%). All agreement rates are lower than the Fulton *et al.* (1987) interviews conducted thirty years earlier, which reported a 71% participation rate. The decline in agreement to participate in later studies may be indicative of a lessening of the public's respect for the medical profession and anyone perceived to be associated with

them.

RECRUITMENT OF NON-DONOR FAMILIES

Non-donor families were approached in the same manner as donor families. However, the main difference was that clinical staff based in the intensive care unit (ICU) contacted them on the researcher's behalf. Although there is no standard practice throughout Britain, the ICU staff usually make the initial request. Two intensive care units, both with large neurological wards (and therefore more potential organ donors) were chosen. Information about the non-donor families, and enquiries whether it would be appropriate for them to take part in this research were sought from clinical staff at the ICU and again permission was sought from the potential participants to approach their GP (Appendix C).

Phase 1 – East Coast (July 2000)

Non-donor families were approached by an ICU consultant in the main hospital, in the first research area that had a neurological ward admitting brain stem dead patients. Additional care was needed in identifying non-donor families from ICU records. Non-donation can occur for two reasons: first, the donor can not donate as medical contra-indications such as Hepatitis C are present, and second, because relatives refused to donate. It was the latter group that this research was aimed at. Table 15, demonstrates the number of patients entering one of the main hospitals involved in this study who were approached with an organ donation request:

Table 15 - (Statistics from Intensive Care Unit)

	1996 - 1997	1997-1998	1998 - 1999
Deaths in ICU	90	70	93
Brain stem deaths	17	21	19
Organ Donors	6	9	10
Refused	7	9	9*
Not Suitable for Donation	4	3	--

*In 1998-1999 donors not suitable for donation and families that refused were combined.

As can be seen from Table 15, the number of brain stem dead patients each year is small, as are the families approached with a donation request. Records at the unit from 1996 to 1999, show twenty-five families refused donation and twenty-four agreed. Given the time parameters of this study (1997 onwards) and the accessibility of available records, twenty two letters of introduction were sent out by the Intensive Care Unit consultant to non-donor families (August 2000). Four were returned, two indicating a desire to take part in the study.⁸² After consultation with G.P's, however, it was discovered both respondents were categorised non-donors due to medical contra-indications, and not because of refusal.

Phase 2 – West Coast (November 2000)

After this initial disappointment, strategies were taken to increase the possibilities of tracing non-donor families willing to take part. The other main neurological centre was approached. However, there were issues relating to database records kept in this ICU, and unfortunately, comprehensive records were not kept of non-donation. Nevertheless, with a considerable amount of time and effort, the health care staff located names and addresses of fifteen potential non-donor families. These respondents were contacted in July 2001, with ten responding (67%) and five agreeing to take part (33%). Only three were subsequently interviewed (although four respondents presented at interviews). One respondent suffered another bereavement prior to interviewing, and another was a case of non-approach, i.e. he was not asked by health professionals whether he would donate. In sum, 34 letters were sent to non-donor families, with a total of fourteen families responding. Seven initially agreed to take part (20%), with four respondents finally presenting at interviews (12%).

Non-Donor Response Rate

Given only 30% families refuse organ donation, the non-donor sample was inevitably going to be significantly smaller than that of donor families (Gore *et al.* 1991, BACCN/UKTCA 1995). Moreover, it was considered likely that non-donor families might perceive the interview as more sensitive and threatening. It is difficult to ascertain whether this was the case, although the initial agreement rates between the samples differed markedly (32% donor and 20% non-donor) suggesting there might be some validity in this claim. In general, numbers in this research are comparable to other studies

⁸² I did receive an e-mail from one individual expressing no desire to take part in the study, but offering a reason for refusing the donation request. According to the e-mail, the health professional that had made the request was, "rather offensive in saying that he did not actually require our permission, but felt morally obliged to ask for it. Not surprisingly this did not favourably influence the request." Obviously there is no way to verify such a response.

conducted in the area of organ transplantation. Limited sample size may be an intrinsic problem faced by researchers in this area due to:

1. The small numbers of people dying from brain stem death every year.⁸³
2. Ethical considerations.
3. Negotiation of Gatekeepers.
4. Preparedness of the respondent to discuss the death of a loved one.
5. Increased likelihood of geographical mobility after bereavement.

All the above factors are likely to militate against a large sample size and every effort was made in this study to increase the sample, in particular non-donor families, within the time and resources available.

Identified areas of Interest: Development of Interview Schedule

The interview schedule (see Appendix A) was designed in order to: i) operationalise the concepts reviewed elsewhere, ii) utilise research findings reported in previous chapters of the thesis and iii) collect demographic information about donor and non-donor families. In light of the preceding discussion, the following areas of interest were identified as particularly salient:

- Social demographics of donor families.
- Reasons for donation i.e. altruism and bodily immortality arguments.
- Wider socio-cultural beliefs about the body, person and death (including brain stem death).
- Perceptions of health professional support and the procurement process.
- Family dynamics.
- Beliefs about organ transplantation (including retrospective views of experiences).

Social Demographics of Donor and Non-donor families

To recap briefly, in the first two chapters I showed certain demographics, such as age, class, education, religion and ethnicity are associated with pro-donation beliefs (B.K.P.A 1994, Gallup 1993, BACCN/UKTCA 1995). However, as previously suggested, such information does little to address the reasoning behind donor or non-donor families' respective decision, nor does it assess the impact of the specific socio-cultural environment

⁸³ No records pertain to the number of individuals suffering from BSD every year in Scotland, although plans to maintain comprehensive records, are currently being discussed by the Scottish Executive Working Party Review on Organ Donation.

on the decision to donate. Demographic information of the donor and non-donor family respondents was collected during this study, enabling contextual background and the location of trends within the sample, i.e. whether mothers shared the same concerns as other mothers or not (See Appendix A, Section A).⁸⁴

Reasons for Donation: Altruism

The interview schedule deals with the issue of altruism because, as I outlined in Chapters 2 and 3, researchers employ the term to explain donor families' behaviour (Fulton *et al.* 1987, Batten 1990, Burroughs *et al.* 1998). Yet, as I suggested earlier, researchers neglected to provide a definition of the concept of "altruism" in their study (Fulton *et al.* 1987, Batten 1990). This provided the rationale for a theoretical focus in Chapter 4, enabling altruistic gifting to be distinguished from other social contexts of gifting. Based on this discussion, I intended to implicitly test the "altruism hypothesis" throughout the interview schedule. This was done by using questions: whether there was involvement in previous altruistic acts (such as voluntary work and/or blood donation); the existence and source of pressure; whether there was an expectation of reward; whether donation was due to empathic concern; the role of obligation and finally, whether respondents would support other systems that did not depend on gifting (Appendix A).

The Social Construction of Death, the Dead Body and its Parts

Additionally, I sought to assess other reasons reported by researchers for donation, that is, relatives believe that through donating, their deceased next-of-kin continues to "live" on, gaining in some sense a "physical immortality" (Bartucci and Seller 1986, Fulton *et al.* 1987). In the theoretical discussion in Chapter 5, I highlighted how the body and its constituent parts are not just biological events or entities. They are, to a certain extent, socially constructed. I argued the "bodily immortality" explanation suggested that, in some way, the person and their organs are perceived to be inter-linked. This could also be correlated with another ambiguous phenomenon in transplantation: the restriction of certain organs. That is, organs considered more important to ideas of personhood, such as the eyes and the heart, were thought to be more sacred, and this increased the likelihood restrictions would be placed on them. Again, the inference is that personal and bodily identity are inter-linked, to the degree they may be thought inseparable, suggestive of a monist view of personal and bodily identity. The restriction of organs and the belief in physical immortality are, therefore, two sides of the same coin. I asked donor respondents whether

⁸⁴ The interview schedule presented in Appendix A is the one used with donor family respondents. The non-donor family interview schedule is not dissimilar, although omits questions such as, "whether they restricted organs." During interviews, the respondents would often cover the desired areas of questioning spontaneously, so the schedule was then used simply as an *aide memoir*.

they restricted organs (Section F). I also attempted to ascertain whether the “bodily immortality” argument could be sustained, through examining responses to questions about the recipients and the status of the donated organ. Bartucci and Seller suggested the need to feel the loved one had achieved a certain amount of bodily immortality was frustrated by the “lack of long-term information about the recipient’s health as well as some detail about their lives” (1986: 404). Nearly all the respondents in Fulton *et al.*’s. (1987) study indicated they had thought about the recipient at one time.⁸⁵ Other studies have also reported that, regardless of the amount of time that had passed after the event, receiving a letter from the recipient was a positive experience, bringing comfort and emotional closure to the family (Bartucci and Seller 1986: 403) (Appendix A, Section G).

Surgery to the Body

Given socio-cultural beliefs regarding the integrity and identity of the body, it was perhaps unsurprising to find the most common reasons given for refusal by the BACCN/UKTCA (1995) was: i) the relatives did not want surgery to the body and ii) the relative(s) feared the patient’s body would be disfigured (also reported as difficult for Bartucci and Seller’s (1986) and Tymstra *et al.*’s (1992) donor respondents). This articulation of concern regarding the identity of the dead also points to a monist view of corporeal and personal identity; the body continues to represent the deceased. Yet do families who object to donation, or have concerns regarding the integrity of the body, also have concerns regarding autopsies? To be consistent, one would suppose those who object to donation would also, to a certain extent, object to a post-mortem. The BACCN/UKTCA study into relatives’ refusal also found those respondents who were planning a cremation, as opposed to a burial, were less likely to emphasize the “wholeness” of the body and more likely to agree to donation (1995: 13). During interviewing, I asked respondents whether they had concerns about the procedures involved in removing the organs, how this compared to an autopsy (should one have been carried out) and finally, whether the decision to donate or not, was related to the chosen means of disposal (Section F).

Brain Stem Death

Moving away from a discussion of the gift, leads into the next area of the interview schedule. That is, it is not only body parts that are imbued with social significance, but the conditions under which the body part was given. Research repeatedly demonstrates confusion about BSD and how it is difficult for both donor and non-donor families to come

⁸⁵ This was also the case for some of the families in the Tymstra *et al.* (1992: 143) study, although the majority of participants stated that they were not interested. As one husband put it, “I never want to know what they did with them

to terms with (Fulton *et al.* 1987, Sque and Payne 1996, Dejong *et al.* 1998). An understanding and acceptance of BSD and a belief in the diagnostic tests is fundamental to allowing donation to proceed. A section of the interview schedule was devoted to such a discussion, assessing the respondents' understanding of brain stem death, whether they were aware of the term prior to diagnosis, if they had any difficulties, and in what way any concerns were resolved (Appendix A, Section C).

Donor Families Informed by Deceased's Past Actions

It was suggested in Chapter 5, that despite the death of the body, the person still continues to have a social existence. Drawing on the work of Mulkey and Ernest (1991), who argued social and biological death are not necessarily synonymous and a person can continue to be socially present, even after the body has died, I argued that for any bereaved family the deceased continues to have a social presence. The effect of this, I suggested, was that donor and non-donor families can base the donation decision on what they believe the deceased would have done, by referring back to their knowledge of past actions and behaviour. Thus, all respondents were asked how they were coping with bereavement, their thoughts of the deceased, and in what way, if any, this influenced the decision to donate or not (Appendix A, Section B).

Health Professional Support

I believed that wider cultural beliefs about gifting, death and the body, have a significant relationship to organ donation, but I also argued, such values should be contextualised and located within the environment an organ donation request takes place in. For example, whether it was likely the decision to donate would be affected by situational factors, such as the role of personal, familial and hospital support and beliefs about the value of organ transplantation specifically (including knowledge of the deceased's wishes).

One area in the interview schedule was devoted to the way relatives perceived the procurement process and the role played by clinical staff. Communication and the establishment of trust with health professionals suggests itself as the primary vehicle by which families can overcome alienation from the medical environment, and accept a diagnosis of brain stem death. Health professionals play a pivotal role in negotiating an organ donation. However, they may not share the same sentiments regarding the deceased's body as the relatives. Due to a lack of previous social relationships with the deceased, health professionals may view the body as simply a potential resource for organs.

[organs]. It's not much of a life if you always go round thinking, 'that's part of my wife walking there.'"

For them, the body is not equated with the living person as it may be for the donor relatives. However, the difference in viewpoints between an objective, Cartesian medical viewpoint and subjective, integrated popular discourse should not be over-emphasised - health professionals may be subject to the same doubts and confusion about BSD as relatives, for example. Can health professionals communicate BSD effectively? Evidence demonstrated professional attitudes remain the “weak area in the procurement process that must be remedied” (Gaber *et al.* 1990: 314). This suggestion of a “weak link” is reiterated in a number of studies, demonstrating not only are that some health professionals are unsure about the status of BSD individuals, but they may be also reluctant to approach families (Younger 1990). Respondents were therefore asked about their relationship with health professionals, whether they felt enough support and information was forthcoming, the level of care provided for the patient and the family, the circumstances around how the organ donation request was made and the value of any follow-up care (Section D and Section G).

Family Dynamics

Health professionals have a significant role to play in negotiating an organ donation request. Yet their influence can either be contradicted or consolidated by the presence and beliefs of significant others – the family. In the absence of a donor card, and knowledge of the deceased’s wishes, the family’s own views are more likely to enter the decision. Apart from the deceased having stated in the past they were against donation, and family fears about mutilation, findings from the BACCN/UKTCA (1995: 17) study suggest that the most common reason for refusal was the family were unsure about what to do. Moreover, an increase in the numbers of individuals involved in the decision potentially opens an avenue to inter-familial conflict (Sque and Payne 1996: 1363) and increased family involvement can consolidate the relatives’ negative decision (Tymstra *et al.* 1992). Thus, appreciating the influence of family members’ beliefs might also affect the decision to donate, and identifying the cause of inter-family conflict is thought to be significant. Therefore, in this part of the interview schedule, I asked the respondents about inter- and intra- familial dynamics. Thus, “who was thought to be the legitimate decision-maker in the family,” “was there conflict in the family,” “who was the source of it,” and “what were the reactions of the wider social network” were investigated. I was interested in, who in the family was considered to have the final say, and the extent of influence, from the family of origin or the family of procreation. I thought, equally important, was an investigation into who was excluded from the decision, and on what grounds this exclusion was based. Finally, after the decision was made, did the next-of-kin tell anyone else, inside and outside

his or her usual social network? Alongside gaining a picture of family dynamics, it helped in determining whether the family received wider social approval (i.e. was this some kind of reward for donation?). Although Fulton *et al.* (1987) reported some donor families received a public *kudos* from donating, others rejected such social approval, treating donation as a “taboo topic” and had made an agreement not to let others know about the decision (Tymstra *et al.* 1992: 143) (Appendix A, Section E).

Beliefs about the Value of Organ Donation

The family’s own beliefs about the benefits of organ donation may well be significant. For example, previous findings demonstrated donor and non-donor families had quite different beliefs about organ donation and transplantation i.e. more donor families than non-donors would be willing to accept a transplant and thought people benefited from receiving one (Dejong *et al.* 1998: 15-18). Those who thought that transplantation was a proven procedure, or if they knew someone who had received an organ, were also more likely to donate (Burroughs *et al.* 1998: 156). I wanted to investigate the source and nature of such positive and negative views, as well as whether this had any impact on the person perceived to be the legitimate decision-maker (Appendix A, Section H).

Donation in Retrospect and Bereavement

Finally, in the last section of the interview schedule, questions turned to how the respondents felt about donation in retrospect (Section I). In hindsight, did they feel that they made the right decision? Both quantitative and qualitative studies suggest donor and non-donor families are equally as likely to regret their decision (Tymstra 1992, Burroughs *et al.* 1998). Why this is the case, is not clear, although it seems to be related to knowledge of the deceased’s wishes. Such a discussion was usually followed by a wind down period, when I encouraged respondents to discuss their present circumstances, to elaborate further on their thoughts of the deceased, and to ascertain how they were coping with their bereavement (Appendix A, Section B).

In sum, I hypothesised that donation revolves around several inter-related areas: gifting, the body, death, clinical support, and family dynamics, and finally specific beliefs about the benefits of organ donation. For example, on the basis of the literature review, this led me to realise there were several areas of potential conflict to be explored with non-donor respondents. I postulated that non-donors were more likely to have known the deceased would object, and/or there were various obstacles such as inter-family conflict, negative beliefs against donation; a lack of health professional support and information, beliefs

about the embodied body; confusion about brain stem death, and a decision they simply could not deal with at the time. Though donor families may be subject to the same doubts and confusion about brain stem death, and fears regarding mutilation of the body, they were expected to have known the deceased's wishes, to have positive beliefs about the value of organ donation, have general family agreement about the decision, and report a high level of health professional support.

SUMMARY

In this chapter, I sought to demonstrate how the generation of theoretical concepts was operationalised in the interview schedule. I considered this outline important, because of the complex nature of discussions in previous chapters, relating to altruism, death and the body. Additionally, such clarification enhances the validity and reliability of the findings by offering a clear exposition of the purpose of the research.

The most challenging aspect of the fieldwork was gaining ethical approval from the NHS trusts involved in the study. Although this took fourteen months to negotiate, addressing the committees' concerns enabled a strong, well-thought out research design, sensitive to both "gatekeepers" and respondents' needs and requirements. Consequently, the level of distress exhibited by respondents was kept to a minimum, and any concerns of health professionals might have had about the study were addressed.

The desired sample size of the donor sample was reached, and the findings are outlined in the subsequent chapter. The limited size of the non-donor sample, however, raises issues about the validity and reliability of the findings. Therefore, the results in Chapter 8 are regarded as a pilot study, a spring-board for further research to be carried out. However, the strength of this research is its comparability; the beliefs, attitudes and experiences of donor and non-donor families can be contrasted, with divergence and similarity examined. Moreover, the uniqueness of this study, one never before conducted in Scotland, makes the findings important even in their most rudimentary form. Asides from the usual caveats regarding the findings of such a small sample (i.e. may not be taken to be representative, and of questionable generalisability) the data will potentially make inroads into a previously unexplored area.

CHAPTER 7: DONOR RELATIVE INTERVIEWS

Introduction

The following discussion relates only to donor families, though an interpretative comparison with non-donor family interviews is offered in Chapter 8. As outlined in Chapter 6, the eventual size of the sample was largely determined by the logistics in locating respondents and their willingness to participate. During 2000-2001, forty-six letters of introduction were sent to donor families, in three different regions. Twenty-nine were returned, with fifteen donor families initially agreeing to take part (32% agreement rate). Nineteen Scottish donor family participants were finally interviewed, as occasionally, another family member was also present at the interview. The diversity of the sample, its biased nature and limited size offer impressionistic accounts, whilst bearing in mind the aim was not to offer a comprehensive overview of organ donation in Scotland, but a full, in-depth exploratory account of donor and non-donor families' beliefs, attitudes and experiences. Where available, comparisons are drawn with similar research, in order to identify similarities and differences.

The findings are presented in two main areas following the structure of arguments in previous chapters. The first will deal with potential obstacles to donation, revolving around death, the body and its parts. The impact of the medical environment, health professional communication, and family dynamics will also be included in this section, enabling an evaluation of their impact. An examination of altruism and gifting follows, including an assessment of personal and familial beliefs about the value of donation, reasons as to why donation occurred, thoughts about recipients and finally, bereavement. The hypothesis is that the decision to donate organs is framed in wider cultural beliefs about the body, death and gifting. I will argue that it is how such elements interact with health professional and familial communication, and specific beliefs about the benefit of organ donation, that will affect whether donation occurs. In the following accounts, pseudonyms have been employed to protect respondents' anonymity.

Demographics of Donor Families

The following information provided about respondents is for descriptive and contextual purposes. A range of demographic data was collected in order to ascertain relationships within the sample (i.e. whether mothers held same or different views to other mothers and/or other relatives) and to locate internal trends enabling the theoretical hypothesis to be tested.

As regards donor family respondents, this was generally a white, middle-aged sample with a disproportionate number of respondents falling into the 35 – 54 age bracket, and only one respondent under the age of 34. Nine men and ten women agreed to take part. Nine of the respondents had some form of further education and/or training. Worth noting, is donor family respondents with some form of medical background within their family were over represented in this sample (n=7). Although this may have biased the research towards a medicalised view of organ donation, it allowed an interesting comparison with other non-medical respondents, the implications of which will be drawn out later in the chapter.⁸⁶ The religious affiliation of respondents fell largely into either Protestant or Catholic groups. Questions were also asked about the regularity of church attendance, given that Burroughs *et al.* (1998) argued a high level of attendance led to an increase in dissatisfaction with the decision to donate, although they offered no explanation for this argument. One donor family participant interviewed (Mrs G), did regret her decision to donate and had a higher level of church attendance (2-3 times a week) compared with the rest of the sample. However, her regret seemed to stem from events in the hospital, and appeared unrelated to religious belief and/or church attendance. Table 16 outlines the demographics of the 15 donors and next-of-kin:

⁸⁶ Just as treating the medical profession as a homogenous group is an over-simplification, yet necessary for purposes here, it is equally the case with the term “medical respondents.” In fact, there was a wide diversity in this group, with some respondents having medical training themselves, whilst others had family members present with some form of medical background. Moreover, the diversity of “medical background” *per se* may also have differing implications. For example, there is a significant difference between having a sister who is a mid-wife, a father who is a medical porter and a wife involved in medical research.

Table 16 – Demographics of the Deceased and Donor Family Respondent

SEX OF DECEASED	AGE OF DECEASED	SOCIAL CAUSE OF DEATH	YEAR OF DEATH	RESPONDENT POST SCHOOL EDUCATION	DURATION BETWEEN RESPONDENT INTERVIEW AND DONOR DEATH	RESPONDENT MEDICAL BACKGROUND	RESPONDENT'S RELATIONSHIP TO DECEASED
MALE	24	MOTORBIKE ACCIDENT	2000	NO	6 MONTHS	NO	SON, MISS A
FEMALE	50	ANEURYSM	1999	NO	8 MONTHS	NO	WIFE, MR F
MALE	54	ACCIDENT AT WORK	1999	YES	1 YEAR	NO	HUSBAND, MISS K
FEMALE	42	MURDER	1999	NO	1 YEAR 8 MONTHS	NO	EX-WIFE, MR X
FEMALE	45	ANEURYSM	1998	NO	2 YEARS	YES [IN FAMILY]	SISTER, MRS M
FEMALE	19	FALL	1999	YES	2 YEARS 1 MONTH	YES [NURSE]	DAUGHTER, MRS C
FEMALE	50	ANEURYSM	1997	YES	3 YEARS 4 MONTHS	YES [NURSE]	NIECE, MRS S
FEMALE	57	ANEURYSM	1998	NO	3 YEARS 6 MONTHS	NO	WIFE, MR U
FEMALE	74	ANEURYSM	1997	YES	4 YEARS 3 MONTHS	YES [MEDICAL RESEARCH]	MOTHER, MR AND MRS J
FEMALE	38	ANEURYSM	1997	NO	4 YEARS	NO	WIFE, MR B
FEMALE	59	ANEURYSM	1997	NO	4 YEARS 1 MONTH	NO	WIFE, MR D
MALE	15	FALL	2000	YES	1 YEAR 3 MONTHS	NO	SON, MR AND MRS E
MALE	50	ANEURYSM	1998	NO	2 YEARS MONTHS	NO	FATHER/ HUSBAND, MR AND MRS O
FEMALE	15	ROAD ACCIDENT	1999	YES	2 YEARS	YES [NURSE]	DAUGHTER, MR AND MRS R
MALE	61	ANEURYSM	1999	NO	2 YEARS MONTHS	NO	HUSBAND, MRS G

The majority of donors were female (n=10). Ten of the donors were, or had been married (Mrs M's sister was not married) and four were young adults or teenagers. The age cohort spanned from 15 to 74 years, with an average donor age of 43 years. Table 17 demonstrates the nature of the kinship connection in more detail. In the donor family sample, this was split between those from the family of origin (n=8) and family of procreation (n=11), with husbands (n=6) the most common.

Table 17 – Donor Respondents' Relationship to Deceased

Husband/ex	6
Mother	4
Son/daughter-in-law	2
Father	2
Aunt	1
Wife	2
Son	1
Sister	1
TOTAL	19

The respondent's emotional relationship with the deceased was not always associated with the nature of the kinship connection. For example, Mrs S was particularly close to her niece, who was brought up as her "wee sister." Equally, Mr X A had a close relationship with his ex-wife, and the split seemed amicable. In contrast, Mrs M had no close contact with her sister and there appeared to be past conflict.

Circumstances of Death

The majority of deaths were caused by aneurysms.⁸⁷ As stated in Chapter 2, due to better road safety and seat belt legislation in the UK, road traffic accidents are a diminishing source of organs for transplant. Generally, because the donor suffered from some form of head trauma they were transferred from the local hospital to the closest neurological centre, for specialist care. Two respondents, Miss A and Mr F, both stated concerns about why their relative was transferred:

⁸⁷ Aneurysms are caused by a congenital weakness in one of the arteries in the brain, where blood clots can form and lead to haemorrhaging and bleeding, and in some cases, death. In discussions with health professionals it was estimated aneurysms may affect between 2 – 12% of the population.

Now I know that man knew and he was trying to prepare us cos I think when they stick patients like David [son] on a ventilator, and I did actually ask my own doctor about this, who I think got a bit rattled. I said to him, 'did they just put him on the ventilator to give us time to get used to it?' And he said 'Oh no that would be highly unethical' and I thought, 'well, I know in [place] they knew that he was an organ donor and I wouldn't like to think that they put him on a ventilator and then transported him to the transplant centre and we're all thinking that he's still going to survive [Miss A: 240 – 244].'⁸⁸

Well to be perfectly honest about it eh, there's a wee nagging doubt in my mind that she only went through for her body parts. That's the only thing I find a wee bit alarming. Well it's what she wanted anyway... [Mr F: 172-174].

Tension arises in these accounts, about whether transference to the main hospital was a choice of treatment for the donor enabling their recovery. Or, alternatively, whether it was undertaken in order to utilise the body for a prospective donation. The suspicion that carrying a donor card might compromise a patient's treatment was mentioned in one other interview, "as I said earlier on with a donor card, I think they would be inclined to say, well 50/50 chance, maybe they would let me slip away as long as they get the organs, I think that's a fear, it could be ignorance," [Mr D: 510–516]. Such comments highlight an apparent unease and mistrust about the health professionals' role in organ retrieval.

Impact of the Hospital Environment and Relatives' Alienation

Suspicious about organ donation, and a potential compromise of treatment, may be exacerbated by an overwhelming feeling of lack of power and control in a medical environment. It was a foreign environment to most relatives interviewed. Mrs K, for example, was unsure about sitting at her husband's bedside in the Intensive Care Unit [ICU]. She "wanted to sit there, but we didn't want to sit there. But when we were sitting, well we were in the way here, but when we went out of the room we felt 'no I should really be in there.' It's a difficult thing to explain" [249 – 250]. Admittedly, Mrs K was not made to feel in the way by health professionals, as "these people know what they're doing and they didn't make us feel that way" [Mrs K: 247].

Equally, some respondents had general phobias about hospitals, "I've never been in hospital and I've never had an operation. And I hate going into hospitals, they make me feel ill" [Mrs M 560-561]. Others, unfamiliar with the main neurological hospital found it "all exits and entrances and trying to park cars and it's quite difficult," [Mrs K: 157]

and “a bit daunting” [Mr F: 190] while recognising the “facilities were good” [Mr F: 228]. Miss A felt most strongly about the hospital she wanted her son treated in, “Oh I wanted him at [place] cos it was like, he was like, at home” [295]. She said she held a rather idealistic faith in the curing capacity of medicine, “I’m at that generation where, mmm.. People don’t die. When something goes wrong and if you get them to the hospital and they’re breathing, that’s it. They can cure everything” [220-221].

Once the donor was transferred to a main neurological centre, or an intensive care unit, they were usually attached to a ventilator. In general, the majority of donor respondents (n=16) mentioned that the ventilator, along with the person’s apparent breathing and warm, pink appearance, caused them little or no distress. In contrast, some viewed it as a benefit; Mr F suggested it allowed time for his son to travel up [217]. Similarly, others thought it “nice everyone got to say what they wanted, while he still looked like Andrew although they knew he was dead he was still kind of warmish to touch” [Mrs O: 278-286]. Three parents had varying levels of difficulties however:

Mr R: You know, if she was totally dead you have less concern, but the fact that she was there with the life support thing, but we know that she was not really alive, but there was a slight concern about that. You know that she was almost still alive, but she was alive and brain dead. So you think how long would the body survive? So just that, not a concern. A slight worry [394 – 401].

Mrs C described her daughter on a ventilator and the atmosphere within the ICU as “horrendous.” Miss A had profound difficulties because, “when it’s something you can’t see. It’s much worse. Cos he’s lying there, breathing, everything’s fine. Not a mark on his body. And you just think that this can’t happen” [Miss A: 223 – 226]. When the suggestion was put to her the ventilator was “breathing” for her son, she answered:

Ah no. You ignore that. They’re still alive. They’re there. OK the machine is breathing but if you switch it off they might be able to breathe on their own. You don’t know that. And knowing that he’s young, he’s 24, he’s fit and never been ill, of course he would be able to breathe on his own [Miss A: 593 – 597].

Respondents’ Understanding of Brain Stem Death Tests

Whilst the donor is maintained on the ventilator, a series of clinical tests is carried out by two different consultants, in order to ascertain whether brain stem death (BSD) has occurred. The timing of the tests, from the onset of coma, is usually left to the physician’s discretion. Indeed, there was a variable amount of time between the relative

⁸⁸ The numbers indicate the position of statements within the transcripts during analysis.

being admitted to hospital, a discussion of brain stem tests, and pronouncement of death (from approximately 10 hours to 10 days).

All reported, with the exception of Mr U who was unsure about precise details, that tests were carried out twice, by two different health professionals. Most respondents, however, claimed to be unaware of what the procedures involved (n=14). Four respondents said they had some understanding, although one thought injecting icy water in the ear, “a bit unusual, it’s not awfully scientific, drip a wee drop water in your ear. A bit medieval” [Mr F: 235] or were concerned that it would cause discomfort. Miss A, crying, said she was worried “it would hurt him [Miss A: 361]. She was also worried her son might still be conscious:

I thought that they had him so very sedated because of all these other injuries eh, that they won’t get a reaction. You know? Because he could still be alive and heavily sedated. You know? You hear about these horror stories where people are actually still conscious but unable to do anything cos they’re paralysed [386-388].

BSD DEATH: THE ROLE OF HEALTH PROFESSIONAL COMMUNICATION

Direct Information

The majority of respondents said the term, “brain stem death” was mentioned to them by health professionals (n=16). This was apart from Mrs K, who claimed she was told there had been “brain damage” [171] and Miss A, who thought words such as “very grave” were used. Whether or not this is a result of an inability to take in available information at that time is uncertain. Due to the stressful nature of events, repeating clear communication about the donor and their condition, was stated as crucial in relatives’ interactions with health professionals. Most of the respondents admitted to being in varying degrees of grief and shock, and found it difficult to comprehend the information provided. Mr B, for example, although initially having some difficulty with the concept of the brain stem death tests, came to understand the seriousness of his wife’s condition:

They were showing me sketches and we’re doing this and that. The best way that one of the doctors said to me was like you’ve got a jigsaw and one piece of the jigsaw is missing and you take it away and all the rest of the pieces are trying to, it doesn’t work. It’s like that with the brain; it’s a very, very difficult thing to explain [Mr B: 449-450].

Hence, there is a requirement for the language to be understandable to the lay person, free from medical jargon and based in concepts familiar to the respondent (e.g.. a jigsaw). Mrs E reiterated the need for this; “they obviously use language that you don’t know.

And I think that every bit of language should be explained. It probably was explained but in this situation you are so traumatised and shaken that you are not taking it in" [195-198].

In addition to a requirement for clear communication, is the need for time so that the information can be understood. Though the respondents claimed they had the term brain stem death mentioned to them, some felt they needed more time to comprehend it. Mr B admitted, "I was all mixed up you see and my head was spinning round" [219-220]. Mrs G's first statement at the beginning of her interview, when asked whether she had any questions was, "I don't actually know what brain stem death was. I just actually thought it was like, well I know that Brian's brain was flooded with blood and that, but I don't know what difference that made?" [Mrs G: 3 – 4]. Mrs G claimed she was unaware her husband was dead, when asked to sign the consent form to donate his organs, "I thought, 'yes I'll sign the kidney donation and if anything happens, *if Brian dies*, they can have his kidneys.' I didn't realise that it set the whole process in motion" [Mrs G: 394-388 emphasis added]. It is difficult to ascertain whether this was a result of the short time period, or how the process was explained, or a combination of both.

Due to the provision of time and clear communication regarding brain stem death, the majority of respondents suggested they did understand the diagnosis. Mr X, for example, when asked what he understood by the term, "brain stem death" made a cutting action at the back of the neck, demonstrating severance of the spinal cord and, "there was nothing else I needed to know. I was quite happy and I told the kids about it and as long as they knew what was going on, they were happy" [104]. Despite her concerns regarding the tests, Miss A was aware her son's brain stem was "crushed," and she drew an analogy between the brain and an egg; "when you get a bump like that, you cannot separate the yolk from the white anymore. It's not gonna get better" [336-337].

In addition, eight respondents recalled having heard the term before. Mrs K, was aware of the term but, "wasn't aware that there were different aspects of the test" [297]. Mrs O [217] thought she'd heard it on the television, as did Mrs M, "television kind of thing. Like obviously they have to do something you know..."[393].⁸⁹ Mr F, however, admitted the term brain stem death, "did not mean much to me. It did not matter much to me either. The fact is that Georgina was dead, eh and that's it. I know the difference between somebody on a ventilator and somebody that is dead" [316-317].

It is clear then, that most of the respondents did not know what the brain stem tests involved, yet the majority said they understood the term after clear communication and time was given. Some thought they had heard the term brain stem death before, and the majority stated they knew what the implications were of the tests (n=18).

Tacit Communication

Families are usually given information regarding the seriousness of their relative's condition, and obviously, this is interpreted and assessed in order to reach their own decisions regarding the outcome. Certainly, most of the respondents had had some indication their relative was in a life-threatening condition. Mr X, was informed by police his wife was dead, although when he arrived at the hospital he was told, "she was still alive but wouldn't recover" [69]. Mr F was also made aware of his wife's condition, and if she did survive, "she's not likely to have any quality of life" [206]. The role of direct communication was found to be significant. However, relatives also picked up on indirect cues that health professionals perhaps unconsciously display:

Mr E: She [a nurse] looked at me with eyes of anticipated grief. You know [150].

Mrs E: I think what they do is just let you down gently. They take you through, but they just let you down gently. But you know more by body language. Their implicit language.

GH: Is it more about what is not said?

Mrs E: It's not just about what is not said – it's what's communicated in feeling. You can feel it, and there's instinct. Your intuition is telling you. I mean I knew it was serious whenever I was told. I did know. My intuition. There was a silence about it.

Mr E: From that moment it was like a growing fright inside you. It was just gathering like a snowball coming to the centre [152-159].

This can also have distressing results for relatives. Miss A thought that prior to her son being transferred to the main neurological centre, a doctor had given her the "distinct impression that, he / I mean I know this is not true and it's a ridiculous thing to say, but I got the impression at that time that he'd written him [son] off" [237-238].

⁸⁹ Others had some form of medical background in the family and also suggested they were aware of the term.

Social Death

Overall, almost all respondents (n=15) made their own judgement as to when their relative had died. The majority did so even before the tests were carried out, and this was based on both explicit and implicit communication from the health professionals. Quite simply, they were prepared for the worst, and the pronouncement of brain stem death by consultants was then taken as a formality, reiterating their own beliefs. Because of direct and tacit communication, the majority of relatives in this study did not appear to have the same degree of difficulty in understanding brain stem death reported in others (Fulton *et al.* 1987, Tymstra *et al.* 1992, Sque and Payne 1996, Dejong *et al.* 1998).⁹⁰ The confirmation of BSD was not only found to reaffirm the health professionals' prognosis, but also the next-of-kin's.

Fourteen of the nineteen respondents stated their relative died *prior* to the brain stem death tests; a phenomenon termed elsewhere in this thesis as, "social death." Usually co-existent with the end of a person's physical life, occasionally, a person can be treated as "socially dead" by health professionals prior to physical death (Sudnow 1967). Here, it is the next-of-kin, not health professionals, suggesting death has occurred prior to medical confirmation. According to Mr F, his wife did not die on Tuesday after the results of the tests, "to me Monday, that's when she died, if she hadn't been on a ventilator she would have died" [326]. Another suggested, "basically I think, my wife died, that was the Thursday the 6th February, but I'm convinced myself that she died on the Wednesday. I think she died on the Wednesday and it was only the machines that kept her going" [Mr D: 226-229]. Mrs C also claimed she knew what the results of the brain stem tests would be, as did Mrs M, who thought her sister died when "her blood pressure etceteras had went sky high. They only did the test to confirm it," [574] and she was only "technically alive" when they last saw her. The topic of social death arose spontaneously in the interviews, as there were no specific questions relating to it. Whether or not the finding was a consequence of respondent hindsight, implying it was not actually the case at the time, seems plausible. However, the pronouncement of social death is also correlated with health professionals' communication:

I was resigned to the whole thing by, Tuesday morning really. I knew what was happening. As soon as, I remember, the consultant came and said, I thought, 'well that's that then' basically she's not coming back from that [Mr J: 223 - 225].

Tensions in Interactions with Health Professionals

Most respondents suggested they were generally pleased with the support offered by health professionals, and were positive about their interactions with them, especially in the main neurological units (n=14). Yet several donor family respondents (n=5) also reported some degree of misunderstanding, or concern, regarding their relationships with health professionals. Tensions in the families' interactions, generally, tended to be incidents occurring outwith the intensive care unit, either at a local hospital (Miss A, Mrs K, Mrs G) or another unit within the main neurological centre (Mrs M, Mrs O). Such incidents caused high levels of distress and anxiety, which persisted post-donation. Mrs M had issues with the clinical staff's inattention to her concerns about a deterioration in her sister's condition. When she told a health professional about her concerns, she felt her fears were dismissed. Mrs M left annoyed "I hate it when they don't tell me anything" [313]. Within a day or two her sister suffered brain stem death and, in a subsequent exchange with the same health professional, she was told she was "obviously quite an astute woman," to which her reply was, "no. I'm just not stupid" [355 - 356]. Lack of information was a common criticism. Mrs K complained that "at no point were we aware it was life threatening really. You know? We weren't led to believe that" [113-114]. Mrs O also reported a break down in communication between herself and the health professionals involved in caring for her husband:

He [her husband] was moved up to the [hospital] on Wednesday, on the Thursday a doctor came in and told me that he had a high chance of taking another brain haemorrhage within six months, he had a higher rate of getting one than I had, but he never told me that he was dying. He never told me that he could die. Maybe they presumed that I would know that. But because they didn't tell us that they robbed me and my son of quality time [Mrs O: 162 - 184].

Although she felt the hospital her husband was transferred to was the "best there is" yet, "they don't tell you anything. They don't say" [162-184]. She felt this lack of communication was twofold: the health professionals did not provide information about her husband's condition, nor listened to her family's needs or concerns. Generally, the

⁹⁰ It could also be the case that BSD as a phenomenon has been prevalent in this society for the last forty years since the Harvard ruling and has eventually come to be accepted. Moreover, it may have also entered public consciousness through the plethora of medical docu-soaps currently on television, which were occasionally referred to in interviews.

need for information and support regarding the critically ill relative's condition is crucial, and its absence can lead to distrust and heightened emotions:

I ended up shouting, as I say, on the day before he died. I asked for a scan or if they would do something, and I went up on the Friday night and they told me that they sent him for a scan. But I don't believe them cos they also told me that he had sat up and ate his tea that night. But I mean the man just could not move. They told me that he had sat up and ate his tea. I thought, "you bloody liar" so I don't think that they sent him for a scan either [Mrs O: 162 - 184].

Mrs O's relationship with health professionals deteriorated markedly, leading her to suggest during the interview that lack of care and support contributed to her husband's death, "I might be right or wrong, but I still say to this day that they killed him [Mrs O: 330-334]. Mrs G also had issues with the perceived lack of communication and care from the health professionals, "I mean there was nothing in [Hospital] that was kindly in any way [Mrs G: 345 - 346]. Mrs O suggested her husband died prior to the brain stem death tests, not due to discussions with health professionals, rather she said she knew when her husband died as, "you could feel the cold in his body. You knew he was dead" and, "as soon as I saw him and touched him he was dead" [Mrs O: 206 - 208]. Miss A also pronounced her son dead prior to the tests, but this was not based on health professional communication, rather, "on one occasion his [son's] eyes were closed. I lifted his eyelid and then I knew, I knew he was away" [349].

Relatives as Active Agents

Although the provision of communication by health professionals has been emphasised in this and other studies, what is also apparent is the relatives' propensity to take an active part in the diagnosis. Respondents did not appear to be passive participants during the diagnosis of brain stem death. Rather, they were active agents looking for evidence of an eventual outcome. In the absence of implicit and explicit communication from health professionals, respondents' turned to their relative's body. They looked for signs of warmth, and "life" in the eyes, traits otherwise associated with a person still alive (Miss A and Mrs O). In addition, relatives also tried to make sense of the technical equipment surrounding the potential donor:

Mrs O: No, no. He didn't have anything in his mouth or anything; they were just keeping his heart going. So he wasn't all wired up, but when you were sitting you could see the numbers going down, whether it said heart beats or whatever, you could see him going down. You could see him slowly dying [270-275].

Mrs K: You know in Intensive care? You know they have this machine that measured the pressure? In the brain? And it should be whatever figure and it was much higher you know than it should be. And you become fixated that you're just looking at this machine all the time and it's going up and up and up...[228-230]

Relatives will search for, assess, interpret and examine available information, directly provided or otherwise, enabling them to make their own judgement regarding the potential outcome for the donor.

Are They Really Dead?

Yet, although death was accepted, indeed arguably pronounced by relatives, tension arose regarding not having a moment of death, as defined by traditional cardio-pulmonary causation. Historically, death is usually associated with cardiac cessation, where the moment of death is ascertained when a person stops breathing. This is not the case with brain stem death, with apparent breathing and respiration continuing. Doubts were raised by a few respondents (n=3) questioning whether their relative was, "really dead." Despite an accepted diagnosis of brain stem death, Miss A's initial reaction to an organ donation request was refusal, as her son was, "not dead yet, [crying] I don't want anybody to touch him" [411] and, "he's lying there, he's ill, you're not touching him" [694]. "You see once they do that they're dead, these people are dead. Because he's not got a heart anymore" [199]. She added:

Do you know the worst thing about saying "yes" to a transplant? The worst thing happens, you know how when you're in the hospital and someone is on life support and they die and the machine and all the lines go flat and you hear "wheee." When you say yes to a transplant they take your person away. You're not there when he dies. You leave the room with him alive. There's no end [Miss A: 270 – 278].

Mrs G was concerned her husband might feel pain during organ retrieval:

Mrs G: [sigh] They just said that they would give him a sedative when they removed his kidneys [crying] and I said that 'if he's dead why are they giving him a sedative?' and they said 'we're not sure that they don't experience some pain and it's just to safeguard that he wouldn't feel anything' and I said 'he can't be dead if he feels pain' and that's just the way my mind works but I'm not a medical person you know [440 – 450].

Not addressing these fears can have distressing repercussions:

Mrs G: Well the chap had confined him and brought him down cos we were having the rosary that night and he said 'would you like to see him' and I said 'yes please' and I mean when they took the lid off the coffin, I have never, never, seen, honestly, a look of terror on Brian's face in all my life. It would have been better if we hadn't seen him like that. But that brought again, obviously they didn't give him a sedative, obviously he felt some pain [454 - 459].

So, on the one hand, the majority stated BSD did not cause any difficulties, yet on the other hand, issues arose regarding whether death had actually occurred. It would appear that cardiac death has not yet been completely displaced by brain stem death in the lay person's understanding of what it means to die.

The Need for Follow-up Care

Mrs G's expression of concerns regarding her husband's death raised issues regarding further communication with health care professionals about organ donation. Communication can also play a role post-donation when follow-up care can allow the donor relatives an opportunity to ask questions they could not think of at the time. A question regarding the need for follow-up care was introduced in Phase 2 of the recruitment process, in response to health professional requests regarding how beneficial donor relatives might find it. Although not standard practice in the UK, it can be an integral part of post-donation follow-up, with transplant co-ordinators making a home visit to the donor families. Other units may leave it as an option, and/or telephone the donor relative. A third of respondents asked agreed that follow-up care might be generally beneficial. This tended to be articulated only by respondents who had received a home visit, however. It was found to be beneficial, as it allowed the opportunity to ask questions, and made the donation seem more sincere and personal:

Mrs E: Oh yeah. I think that it's very important.

GH: Do you? In what way?

Mrs E: Because they can come and help you by answering the questions that you couldn't think of at the time. They come in later [590-593].

GH: Have you found that a good thing?

Mr O: It makes it sincere and personal.

Mrs O: They just didn't take his organs and go "right bye, bye." That's what it was [397-425].

Conversely, common responses from other respondents who had not received a home visit suggested, “it’s done and dusted,” (Mr and Mrs J: 457) “has she not got enough to do without bothering me?” (Mrs S: 806) and, “I can’t really think what I would gain from it” (Mrs C: 688).

Communication by health professionals can have a positive impact in several areas of organ donation. First, it can help in overcoming the relatives’ alienation from the medical environment they find themselves in. Second, it allows a determination of the potential donor’s condition, encouraging the pronouncement of death by the relatives. Finally, post-donation, it can allow issues to be resolved and make the donation seem more “sincere.”

Clearly, organ donation is not an individual decision, but one affected by the dynamics of groups, both inside and outside the family circle. Although health professional communication can have beneficial consequences, making relatives’ experience in intensive care units easier, it can also exacerbate relatives’ grief and uncertainty through a perceived lack of information and care. Whether or not this actually leads to a refusal of donation is unclear. In this sample, organ donation subsequently occurred, so although health professional communication is crucial in meeting the needs of relatives, it is not the sole determinant in influencing an organ donation decision.

THE ROLE OF COMMUNICATION: FAMILY DYNAMICS

As a group decision, organ donation is susceptible to the impact of external influences from the medical environment, but it is also internally affected by the beliefs and attitudes of other members in the family. Conversations within the family can pose an obstacle to donation, with an increase in familial involvement found to be significant in increasing conflict about the decision (Tymstra *et al.* 1992, Sque and Payne 1996). In this research, various members of family and friends were present at different stages of the donation process. The request was put to the legal next-of-kin, usually a spouse, with other members of the family of procreation involved in the decision, with little or no input from the family of origin. Ten of the respondents were married and, in all cases, the decision was left to spouses, occasionally in consultation with their children. Equally, in a normative sense, the perceived legitimate decision-makers were the family of procreation, the husband or wife at the pinnacle of the decision making hierarchy, followed by elder

children. Consultations with children were treated as crucial to the extent their views could swing the decision either way:

Mrs O: At the end of the day he had the last say [son]. It was up to him.

GH: Why?

Mrs O: Cos I wouldn't hurt him [253- 255].

When members of the family of origin were occasionally consulted, they tended to assume it was a decision for the donor's wife or husband to make, with even estranged partners considered to be legitimate decision-makers by other family members. Mr X and his children made the decision to donate his ex-wife's organs, despite the fact Mr X had been separated from his wife for five years. His sister-in-law (considered legal next-of-kin) had suggested, "it was up to me" [Mr X: 93]. Various members of Mr F's family were present when his wife was taken to the main neurological centre. However, like Mr X, Mr F's sister-in-law thought it a decision that should be left to Mr F and his children. When there was no family of procreation present, health professionals approached the family of origin. In the case of donor children, both parents made the decision, occasionally with input from other siblings. Miss A, who was estranged from her husband, was the exception to this. She felt it was only her decision to make, due to her estrangement from her husband and the strength of her maternal role. In Mrs M's case, her sister had no spouse or children, and she was considered the legitimate decision-maker, both in a legal and normative sense, offering to donate her sister's organs as a result of previous discussion and agreement with other members of the family of origin.

Tension

Although most of the respondents asked (n=16) reported no direct conflict or disagreement within the family regarding the decision, there was a certain amount of tension apparent in others:

Mr F: In fact I thought he [stepson] was going to throw a tantrum when I said it to him. I didn't want it myself. Really I was leaving it to him. If he had said no then that would have been enough and I would have said no.

GH: Why do you think it was his decision?

Mr F: Oh no. It wasn't his decision. It was a matter of all our decision. As it stood at that time eh. My younger son wanted it to happen. I didn't really, you know I could be swayed easy enough. So I left it to [stepson] to have the casting doubt then. We've all got to have our say. Eh, and then he came back and said 'aye' if it's what his mum wanted then it's what she would have. And that's fair enough [177-184].

Exclusion

Equally some of the people present during the donation request were not actually welcome:

Well I wanted to ask questions and what she did do [transplant co-ordinator] was come in this room with twenty people in it. And eh, I probably couldn't speak at that time anyway. Eh and there were questions I wanted to ask but I didn't want to ask them in front of anyone else [...] I also felt a bit miffed about [...] this was my son and why are they doing this in front of all these people? I mean I don't care if his auntie thought it wasn't a good idea if I thought it was. Why are they including her in this conversation because this is a personal, private conversation? He's part of me. [Crying] He's mine [Miss A: 504-510].

In the case of Miss A, tension within the family was already heightened with the presence of her estranged husband and new partner. Her family, including her ex-husband, were not involved in the decision to any great extent, "well they can't interfere" [Miss A: 437] and, "he [her husband] was in a different room" [415]. Although her daughter reassured her of her son's wishes suggesting that, "mum that's what he wanted," [437] Miss A had already had a heated exchange with her daughter regarding her son's donor card:

Miss A: That was another thing my daughter did and I nearly flipped out cos when we were up [place] when we're all thinking you know that he's got broken bones so you know we can cure them, that's not a problem, he's unconscious, ach, he'll be round later. And she's out with his donor card you know? I could have slapped her cos it was almost like he's written off.

GH: Uh-ah.

Miss A: But I thought it's not the time to start causing a fuss in a place like that when they're under pressure. It's funny how I'll never, ever forget that she did that. I did say to my sister, I think she thinks she's taking part in an episode of ER [399-406].

Those excluded from the decision, for one reason or another, again tended to come from the family of origin (n=2).⁹¹ Mr X's ex-wife's brother was excluded as he had taken an allergic reaction to a "measles jab when he was 5 or 6 and he didn't grow up after that" (Mr X: 166). Mrs K's reason for excluding her husband's two brothers was also straightforward. When they were informed of the condition of her husband, in her view they chose not to visit, and "I felt it was up to my son and I" [380-381].

⁹¹ Although Mrs C admitted that her other daughter was excluded because of her young age. She was nine at the time of her sister's death.

DISPOSAL AND MUTILATION

Tension about organ donation within the family appears to stem from two sources, first, previous family conflict and, second, family members' uncertainty about organ transplantation. The origins of such uncertainty were also identified – whether the procedures involved in organ transplantation compromised the integrity and identity of the dead body. Two thirds of donor family respondents reported concerns about whether organ removal procedures would compromise the body's integrity:

Mrs E: later on. In fact not even so long ago it flashed in front of me that his [son] body, which I'd lain with, touched and stroked, wouldn't have looked the same. That he would have scars. That he would be cut. And that struck me like a lightning flash and that was only a few months ago [312 – 314].

Four donor relatives initially refused donation because of such concerns:

Mrs C: My initial reaction was no. I don't want to. I mean I don't have a problem with it [organ transplantation] for myself. If that were to happen to me I would give, I would donate organs as well. But when it's your child. I don't know. It doesn't seem right that you should do that.

[...]

GH: what was it, when you say that it's your child and it's not right, can you elaborate more for me?

Mrs C: I just think the whole idea. Your child has just died; you're in a situation, which, never in your wildest dreams would have expected to happen to you. You don't expect your child to die before you. You kind of, you think, you know just the fact that they were going to cut her open and take her heart out [389 – 409].

It became apparent for some donor families, particularly parents, there was tension between donating the organs and the procedures involved in organ removal. For example, although Mrs E recalled not having any concerns regarding the procurement procedures at the time, she felt "very sad" that, "I wasn't there when they did the operation. That struck me. That he'd [son] gone through this surgery" [315–323].

Parent's Attachment to the Dead Body

Due to the strength of feelings attached to the body, an apparent contradiction arose between an acceptance of death, yet having to leave the body. As stated earlier, the majority of the relatives suggested their next-of-kin had died prior to the brain stem death tests, but not being with their relative at death or immediately after was reported as difficult (n=4). Significantly, it was mothers (n=3) who mostly articulated this anxiety, suggesting a continuation of a powerful maternal role in events happening to their child

after death. Mrs C found it extremely difficult to leave the hospital wanting “to turn round and run back in again” [531-532] to her 19 year old daughter:

Mrs C: I think the main issue for me about the organ donation was that I was in a bit of a quandary about it really, because the thing is she was on the ventilator right?

GH: Uh-ah

Mrs C: So [pause] that was what worried me [crying].

GH: In what way?

Mrs C: Because [pause] I wanted to be there when they switched everything off right?

GH: Uh-ah.

Mrs C: And I wasn't

[...]

Mrs C: I think the organs were to be taken, took that away from me. Well not taken away but not as much as a possibility as it might have been. If I had said no. No organ donation. Right? We probably would have switched the ventilator off before we left the hospital [479–495].

When asked whether she would donate again, Mrs O was unsure, because the implication was she would be donating her son's organs. She explained the difference between how she felt about her husband and her son:

It's your children. Your children are so different to when it's your partners. Your partners are strangers that you married, they've no blood ties to you, and it's completely different. I would die for him [points to son]. I said that to Andrew, 'see if it was someone pointing a gun and 'choose between your man and your son' I said, 'you're dead.' He was like, fair enough [laugh] [Mrs O: 499-502].

Her comment gives some indication of the strength of the maternal role. To Mrs O, there was an intrinsic “blood” connection between her and her son, making the relationship qualitatively different to that between her and her deceased husband. The strength of the maternal role, namely a continuing desire to support and be with your child in life, continues after their death. In part, this could be due to the “blood connection” between mother and child arising from the experience of pregnancy and birth. Mr E made this point, when describing the differences between his own and his wife's [Lesley] grief, after the loss of their son:

Mr E: Sorry, but eh, the other gender thing is that, you want to be close, and you can hold, but Lesley's grief is Lesley's grief. And the gender thing for Lesley is I mean I could hear her crying for the boy, and crying through the night. But I mean she birthed the boy, it was a real push, with the assistance of midwives and all the rest of it. But this was a new delivery she had to push, with no mid-wife, and she was going to have to push this boy, out into the great beyond. And there is a psychophysical, gender issue there for Lesley. I think the thing is trying to process that [425 – 432].

Alder Hey and Bristol

In the twentieth century the death of a child is particularly emotive for both parents. Due to medical advances, modern Western society is characterised with a low birth and child mortality rate. Indeed, Mrs C's statement suggesting it "doesn't seem right" a child dies, highlights a taken-for-granted assumption that parents die before their children. One father poignantly summed up his pain at losing a child:

But the part of grief of children is that it is out of order. Them going before us. There's almost a desire to want to go through the door to be with them, at times its burning, to be wherever they have gone - you can understand the option suicide - quickly [Mr E: 397 - 399].

Ties and feelings of protection continuing beyond a child's death may, in part, explain parents' reactions when children's organs were removed after post mortem, without knowledge and permission, at Alder Hey and Bristol Hospitals (discussed previously in earlier chapters). Although the issue of informed consent in taking organs was found to be significant, evidence presented here additionally suggests such actions may have transgressed strong emotional bonds with the dead body. Any perceived transgression of a dead child's body is viewed, to a certain extent, as equal to a transgression of the living. The highly distressed feelings of the parents involved in Alder Hey are testament to this. Such bonds, therefore, continue to inform the acceptability of intrusive practices on the dead body and cultural beliefs about the integrity and identity of the deceased.

Such bonds are not necessarily always based on the kinship connection between parent and child. The potential for refusing donation, past and future, was discernible in donor family accounts, and seemed to imply that the closeness of the social relationship with the deceased was key to understanding potential refusal. Mrs M, who offered to donate her sister's organs, would not have done the same after her mother's death, 13 years previously, "I probably had, like a very close relationship with my mother. Like she was my friend as well. You know what I mean? I wouldn't have liked her to have been cut or

anything like that" [188-197]. There was history of past tension and conflict with her sister, and Mrs M did not consider them to have a close relationship. Hence, fears about mutilation of the body may not only be about the nature of kinship, i.e. the strength of the maternal role, but may also relate to the individual's perception of the relationship to the deceased. On a fundamental level, the relationship to the person continues, if one believes the person is embodied in the newly dead body.

Post Mortem

In order to compare the concerns expressed about organ removal with other surgical procedures conducted on the dead body, questions were raised in the interview regarding the acceptability, or otherwise, of post-mortems. Those unconcerned about a post mortem, generally emphasised the perceived mandatory aspect and benefit of establishing cause of death.⁹² Only two respondents in this study, who expressed concerns about mutilation and transplantation, stated anxieties regarding a post-mortem.⁹³ Both comments, are examples of fears regarding the integrity and identity of the body. Again, a mother suggested:

Miss A: When she [nurse] said about the post mortem thing I said no. I'm not keen on anything like that. I said that was enough. Cos I wasn't for it [donation] in the first place. And she said nothing will be happening, it's straight forward, it's simple, there will be no intrusive anything [633 – 635].

Mrs M restricted where the post-mortem could be carried out on her sister, only agreeing to a post-mortem on the "operation" attempt to stem the haemorrhaging. Moreover, she refused an offer to return and visit her sister after the organs were taken. She justified this by suggesting that, "you have a picture of someone, what they're like and you know [...] if I had gone back and seen anything that would have just freaked me out I think" [412-415].

Organ Restriction

It is clear that the dead body is imbued with an emotional significance, which implies that it is not altogether separable from the living person. The bonds relatives have with the deceased continue, and concerns about procedures to the body, are linked to these feelings. Whether or not such bonds persist after the body is disposed of, will be returned

⁹² In answer to the question whether they had any objections to a post mortem being carried out, other respondents, suggested they did have concerns, only because the cause of death was apparent and they didn't see the need for one.

⁹³ Generally, findings seem to support Sanner's Swedish study (1994) demonstrating autopsies were the more acceptable form of surgery to the dead body.

to later in this chapter. For now, attention turns to the gift itself – the organs. Insofar as the dead body is given an emotional and cultural significance as an embodiment of the person, so too are its parts. Just as this led to concerns about the violation of bodily integrity and identity, the same phenomenon led to restrictions on what organs could be donated. The strength of symbolic and aesthetic beliefs attached to certain body parts, such as the eyes, caused almost a third of donor relatives to refuse to donate them (n=5). Restriction of the eyes is a relatively new finding, yet discussions with health professionals also suggest, in their experience, approximately 30% of donor families will restrict the eyes. In this sample, the eyes were the only organs restricted.⁹⁴ For example, “But eh, I did not want them to take his eyes. I had visions of seeing him afterwards with hollows” [Miss A: 533 – 534].

The visual element of also being able to *see* a person’s eyes was thought important, “whether I felt that that’s a visible part if you like, whereas it doesn’t matter what goes on underneath” [Mrs K: 362 – 366]. In everyday interactions, the eyes play a significant role in communication, and have become synonymous in everyday discourse as the “windows of the soul,” a visible expression of the less tangible aspects of personhood:

Mr F: And we decided that they could have everything but her corneas. That was just something I didn’t want. [...] The thought of somebody cutting her eyes. She’d lovely eyes [crying]. She always used to say eh..

GH: Take your time.

Mr F: That your eyes were the gateway to the soul [330–333].

Notably, unlike other studies, there was no evidence of anyone restricting the heart (Fulton *et al.* 1987). The heart may still be symbolically perceived as the organ that feels emotion, but the eyes show emotion, providing not just *sight*, but *in-sight* into the person. Three donor family respondents said they would not meet the recipients because of the corneal donation. Mrs O suggested, “see whoever got his eyes, I mean it’s not a total eye that they use, is it? I don’t know. I think I would be looking for traits of Andrew [husband] in them” [378 - 384]. Apart from offering insight into the person, a few respondents suggested sight served a further function – an ability to see in the after-life:

And eh, my major concern was that they were gonna take his eyes. And the reason for that would be, that [crying] he wouldn’t be able to see anymore. I mean I know that’s ridiculous [Miss A: 515–517].

⁹⁴ Mr U, although not restricting any of the organs regretted that he hadn’t restricted his wife’s eyes. When he went to

Removal of the eyes, Miss A suggested, would mean “holes” would be left and they might also be required for a purpose, “to see” in the afterlife. Whilst simultaneously admitting this was “ridiculous,” this belief is prevalent in non-western societies that emphasises holistic versions of embodied personhood. As was outlined in Chapter 5, Japan has significantly lower donation rates, partly, because of religious and cultural beliefs relating to the continual integration of bodily and personal identity after death. If individuals believe a dead person needs the dead body or parts of the body in an after-life, they are less likely to donate.

Reassurances

In order to deal with concerns regarding the violation of the dead body’s integrity, some respondents developed coping strategies. Although Mrs M was in favour of donation, to the extent she offered to donate her sister’s organs, the actualities of removing them caused her anxiety. To try and reduce this dissonance, she said that “I just didn’t want to know what they were going to do. Not what they were going to do, I knew what they were going to take. But I didn’t want to know how they were going to do it” [552-553]. Others made implicit assessments of the health professionals, and whether they could care for the deceased, again emphasising the persistence of bonds. Miss A expressed this:

You make an immediate assessment of who that person is. Not what they do or what they’re there for. That’s why it’s easy when you deal with somebody like Dr G., [...] and the girl [transplant co-ordinator] cos it’s such a position of trust. So when somebody is going to be looking after him [son] you immediately assess ‘can they do that?’ [480-483].

The role of health professionals was found to be pivotal, and reassurances needed to be offered regarding the procedures of removing of organs:

And they explained to us at the hospital and the transplant co-ordinator was absolutely super and I really had, although it was just a short acquaintanceship if you like, a really good [...] I could trust her. I felt [...] she said that she was there to represent the patient and make sure that everything was open and above board and there was no ‘ransacking of the body’ if you like. It was a clinical operation and everything would go according to any other operations as if he [husband] was still alive [Mrs K: 398-401].

Trust and tacit feeling were linked to the perceived level of care for the donor, and formed an integral part of facilitating the donation process. What appeared crucial, was their loved one was not simply treated as a resource for organs:

view the body, there was bruising all round the eye area.

Mrs G: So he took us up to the intensive care, [pause] and the first thing when I went in was I think he still had his trousers on. They had taken his wallet out of his pocket and they had taken out the kidney donor card and it was propped in front of his wallet. Cos when I went in the first thing I saw was Brian and I saw that [crying]. I mean when I think about this I really feel very, very angry. We were there. They had no, I don't feel they had any right to take that wallet out, to go in it, and take his card [339-343].

Inappropriate usage of a word like "harvesting" caused the next-of-kin some consternation and anxiety. Mrs S, a retired nurse, although not having any worries about the removal of organs, did "feel it hit home" when a colleague mentioned the word, "harvesting." She explained, "if it had been anybody else [...] but a relative, I think, mattered" [674-689].

Medical Background

Perceptions of the dead body can affect the decision to donate and what organs can be donated. Some respondents were more likely to articulate fears about what would happen to the deceased's body, and to restrict certain organs considered important to personhood, such as the eyes. So, the newly dead body remains to be the site of personhood and, as such, relatives continued to be concerned about what would happen to it. In contrast, health care professionals do not have the same emotional ties to the deceased, and may not perceive the body as an embodiment of the living person. Indeed, the influence of a medical background and training in some of the donor relatives did cause significant differences between them and other respondents in the sample ($n=7$). Whilst not wishing to construct over-simplified dichotomies between two homogenous groups, two different patterns of belief systems were discernible between medical and non-medical respondents. Medical respondents had the same social relationship with the deceased, and arguably, the same continuing social bonds, but they were less likely to have concerns regarding the procedures involved with transplantation. They were also less likely to restrict organs, and more likely to perceive the body as "just a body," a belief co-existent with the ethos of transplantation dependent on a separatist, dualist version of personhood. The question is, why were medical respondents less likely to share the same fears as other respondents?

GH: And you didn't place any restrictions?

Mr J: No.

GH: Why not?

Mr J: Well what's the use to her [laugh]. That's basically the idea behind it, as they say "they can't take it with you" so might as well use them. *I mean it's a body. It's not really a person that you grew up with or anything like that* [292–299 emphasis added].

It would appear medical respondents were less likely to perceive the newly dead body as the person. The quotes above, construct the body as a material entity, not to be equated with the person it once was. The body is a shell, akin to a machine or vehicle within which the person or soul is housed; as discussed in Chapter 5, a view known as Cartesian Dualism. Disrespect to the dead body is not disrespect to the person as "the body is not the person." Donating organs, therefore, is akin to stripping parts of a car, once the driver has got out. A medical respondent stated precisely this:

Mr J: For me I just look at it like, somebody that is brain dead whatever, is just like a broken car. A broken car itself is not going to be of use, but you can cannibalise the parts for something else [694–696].

It is unclear why they have a greater propensity to have such a view, though it may be related to the development of clinical detachment and an awareness of the benefits of modern medicine can have:

Mrs S: I just feel that if I can help somebody. You know? I suppose I've seen people die because there was nothing anybody could do. Medicine has advanced so much. And I just feel that anything they can use [...] *they don't need it any more* [66– 671 emphasis added].

These respondents were equally sceptical about events at Alder Hey, suggesting it was, "a lot of media hype" [722] and questioning the emotional attachment relatives placed on burying parts of the body:

Mr J: We have to bury the heart, then we've got to bury the bits as well. It's like, I hate to say it, but it's like burying bits of meat I'm afraid.

GH: Sorry. Bits of meat?

Mr J: *It's dead organs. It's not the person* [730 – 734 emphasis added].

Notably, this is a view similar to the "butcher shop" analogy presented by Mr F, a non-medical respondent:

Let's have half pound a heart, three quarters of a pound of liver. Eh I'm afraid that's in me. I'm just trying to be as honest as I can and that's the way I feel about it. I could change my mind but I can't see me changing my mind in the next couple of years or so. Until I'm maybe certain that it's what I want and not because I felt that Georgina would [...] and I would hope that my next-of-kin whoever it would be at that time would eh, respect my wishes in it as I did for Georgina [Mr F: 717-723].

However, Mr F's equation between the "meat" perspective as sold in a butcher's shop, and organ removal, is linked to his abhorrence of the perceived disrespect to the dead body. In short, such an analogy in his case meant he initially refused to donate his wife's organs and will refuse to donate his own, "I know it's not but it's too much like a butcher's shop to me. I know it's not that. I know they do it well and that they do it with care and respect. But that's the way I feel about it" [714 – 715]. To Mr F, equating a human dead body with any other dead animal, showed a lack of respect to the deceased, to the living person once entwined with their body.

This discussion of the body and its role in organ transplantation shows how contrasting views of the relationship between a person and his or her body are constructed, depending on differing social needs and beliefs. Simply, whether a person *has* a body, or *is* the body. On the one hand, the newly dead body can be equated with the living person it once was, and the bonds between bereaved and deceased remain intact posing potential obstacles to donation. Such bonds can be particularly strong between parent and child, making the decision to donate difficult, especially for mothers in this sample. Yet, on the other hand, those with a medical background, either themselves or within the family, seemed to have more of a dualist ideology regarding the newly dead body and a strong belief in modern medicine. The person was not to be equated with the newly dead body, and the organs were simply, "pieces of meat." Such dichotomies between dualism and holism are not impermeable. Those respondents with a medical background, either themselves or in the family, were still subject to such cultural influences. For example, Mrs C was a trained nurse, and a mother who initially refused to donate because of fears about violation of her daughter's body.

REASONS FOR DONATION

Given the discussion of obstacles that beliefs about death and the body cause, the aim now in the following sections is to examine when and why donation occurred, examining the respondents' belief systems regarding the value of donation, and whether altruism or bodily immortality as explanations can be supported. Previously, it was argued that the main obstacle to donation in this sample, in addition to the influence of health professional and family communication, was the construction of embodied personhood and the continuation of social bonds. In this research, these potential obstacles did not hinder donation occurring and, this therefore, raises interesting questions as to why donation *did* occur. None of the respondents used the word, "altruistic" or "altruism," to describe their actions though there did appear to be a high incidence of previous "altruistic behaviour" in the sample. Respondents were asked about examples of previous "altruistic" behaviour as Burroughs *et al.* (1998) suggested, donor families were more likely to have committed previous altruistic acts, such as giving blood, and/or involvement in voluntary work. Six of the fourteen respondents gave blood, which is a significantly higher proportion than that found in the general population. Eight respondents admitted to varying levels of voluntary charitable activities. Such findings are contestable, and may be a result of the respondents' offering socially desirable answers.

In Chapter 4, I argued there were theoretical difficulties in maintaining altruism as an all-encompassing explanation for donation behaviour. Several criticisms were offered, however, the main ones being that there is a vast array of motives that individuals can act from and self-interest, reciprocation and obligation may play a part in donation, though it is unclear in what ways. In order to assess the altruism claim, a working definition was also previously offered, i.e. altruism is a voluntary, other-motivated action without expectation of reward. This may not be a definition universally agreed on, but it is similar to the principles the present voluntary, anonymous non-reciprocal gifting system is based on. It is also a definition reached through theoretical argument, and potentially verifiable by research. Do elements of the "altruistic" system correlate with reasons donor families offer for donation? The definition was broken down into three further areas:

1. Was donation *voluntary* or *obligated*?
2. Was any reward *expected* or *received*?
3. Did the reasons offered for donation involve *thoughts of the recipients* or *not*?

Attitudes toward Donation

Prior to an examination of the reasons respondents gave for donation, it is important to note there was an extremely high level of agreement about the value of organ transplantation. Table 18 outlines whether the deceased and/or respondent had a donor card, and whether they initially agreed to donation, and if a future donation would be likely:

Table 18 - Donor Card Ownership and Effect on Agreement to Donation

RESPONDENT	DONOR CARD	DONOR	DONOR CARD	*AGREED TO DONATION	FUTURE DONATION LIKELY
MRS C	*N/A	DAUGHTER	NO	NO	**N/A
MR F	NO	WIFE	YES	NO	NO
MISS A	NO	SON	YES	NO	**N/A
MR AND MRS O	YES [POST-DONATION]	HUSBAND	NO	NO	YES
MRS M	YES [POST-DONATION]	SISTER	YES	YES	**N/A
MRS K	NO	HUSBAND	NO	YES	YES
MRS S	YES	NIECE	YES	YES	YES
MR AND MRS E	NO	SON	YES	YES	YES
MR B	YES	WIFE	YES	YES	YES
MR X	YES	EX-WIFE	YES	YES	YES
MR U	YES	WIFE	YES	YES	YES
MR D	NO	WIFE	NO	YES	YES
MR AND MRS J	YES	MOTHER	NO	YES	YES
MR AND MRS R	YES	DAUGHTER	YES	YES	YES
MRS G	NO	HUSBAND	YES	YES	NO

*At initial request

** Not asked

There was a strong pro-donation pattern in the sample, for both deceased and respondent. Approximately half of respondents and donors had donor cards, the presence of which can make the donation decision more straightforward. Mr X's ex-wife had carried a donor card and to him donation was clear-cut, "the decision had been made like years before. She died I would have donated. If I died she would have donated" [308–309].

Likewise, all respondents asked thought that recipients benefited from having a transplant, and would be willing to accept a transplant themselves. Pro-donation beliefs were also related to the influence of a medical background - all respondents who approached health professionals with an offer to donate, had some form of clinical or medical background either themselves, or within the family (n=7). Whether or not this is a direct, causal factor is unclear, though it is possible to assume a relationship between medical knowledge and perceived benefits of organ transplantation:

GH: So when did they start talking about brain stem tests? The Tuesday?

Mrs J: That was the funny bit [laughs]. Already knowing what the outcome was going to be I'd suggested to him [husband] that he donate the organs [Mr and Mrs J: 226 - 229].

However, most respondents were approached with an organ donation request (n=12). Again, some found it difficult to remember precise details. Usually, a consultant made the request, mostly in a private forum. The request was general, along the lines of "have you considered..." or "have you thought about...?" often after the outcome of the brain stem tests. Two issues arose regarding the request. First, one respondent was upset it had been made in a public area in the hospital and, second, difficulties were more likely to occur if the request came before the outcome of the tests or too soon after:

Mrs G: But I thought they would fight to save his life. It was only in the event of his death that you get that. And they did say, we don't usually ask people to sign it so early. And I said, "well I know that is what my husband would want," I knew that's what he wanted. But I didn't, if she had said to me this would actually speed it up. But I did think afterwards that they shouldn't have done that. They should have left that for a while. They could have kept Brian on a life support for a day or two days and given us time to come terms with it [496-504].

In contrast, approximately half the donor relatives said their immediate reaction to the mention of organ donation was positive, and some like Mr X, made the decision immediately. Not only was the initial response positive, so too was the initial decision, with only four respondents immediately refusing. Miss A, Mrs C, Mr F and Mr O,

initially refused and Mrs G, Mr F, and Mrs O would potentially refuse a future organ request. Although the majority suggested that they would make the same decision again, potential for refusal appears to be related to uncertainty about donation, in the first instance. Apart from Mrs G who had a uniquely distressing experience in her interactions with health professionals, reasons for potential and initial refusal were related to concerns about bodily integrity (Mr F, and Mr O and Mrs O). Yet, regardless of any difficulties and concerns, nearly all respondents, reported positively about the donation experience.

Agreement was strongly related to the presence of a donor card: two respondents who initially refused (Mr F and Miss A) agreed because they knew the deceased carried a card. Most respondents had a donor card or made their wishes known, as had the deceased. They therefore initially agreed to donation, and would donate again. Moreover, the presence of a donor card can serve to reassure relatives about donation:

Mrs M: I thought 'oh gosh, what if she didn't want anything like that done?' We've no idea. And then I went into her house and felt so much better after that.

GH: Because?

Mrs M: She had actually done that [had a donor card]. I said to one of my friends 'you'll probably think that I am going mad now but with this kind of thing, what if there is a heaven and she met up with my mother? And she went to my mother 'look what she's done to me, she's taken all this away from me' [organs] [498 – 513].

Obligated Donation – Carrying out the Deceased's Wishes

A positive belief system, and the presence of a donor card, are both influential factors in making the decision to donate an easier one. With support and communication from health professionals and other family members, concerns about transplantation procedures may be easier to overcome. Yet, although contributory factors, they do not sufficiently explain why donation occurs in cases where one or the other is not present. Neither does recognition of pro-donation beliefs, and the deceased's donor card, aid in locating organ donation relative to other forms of gifting behaviour. Were the donor families acting voluntarily, without thought of reward and concerned with others' need? Or is the decision more about *obligation*, *self-interest* and *reciprocation*? Taking the latter three elements separately, sociological interpretations of donor family accounts enable a deeper understanding of whether, and how, each plays a part.

Sources of Obligation to Donate

Potential areas of pressure were explored with respondents, in order to ascertain whether they felt they were under any obligation to donate. For example, the limited availability

of time may not have allowed the opportunity to fully consider the donation request. Most reported they “were not rushed” [Mr F: 303], though remembering the available time to make the decision proved difficult; estimates ranged from an hour or so [Mrs C: 385] to a day or two [Mr D: 195] and if they required more time they were given it [Mr F: 277]. Mr B suggested that had he been offered any more time, he might have changed his mind, though could not offer a reason. The majority of the interviewees also reiterated the sensitivity of the request:

GH: How was the request made?

Mr X: Oh yeah. You know they didn’t bump into me in the corridor and ‘oh we have a dead person there you know and we want to take their organs’ [laughs]. It was a bit more sensitive than that [146-148].

Transplant co-ordinators play a crucial role in facilitating the donation process and the majority of families asked (n=16) were happy with the role they played. Some realised that they were in a “terribly difficult position” [Miss A: 486]. “Obviously approaching the relatives of the deceased, or the recently deceased, but yeah she was absolutely fantastic” [Mr and Mrs J: 333 – 337]. One feature mentioned to be important was the transplant co-ordinators did not wear a uniform, so “it was easier to speak to them” [Mrs C 453], breaking down barriers between medical and non-medical spheres.

Neither a lack of time, nor the manner in which the request was made, were identified as direct sources of pressure by the respondents. However, one source of normative pressure was distinguishable; the deceased’s donor card. Some respondents, like Mr X, did not consider themselves to be acting from their own beliefs, but were influenced in the decision by knowledge of what the deceased wanted. In effect, the relatives considered themselves to be carrying out the deceased’s wishes. They were partaking in a role and donation can, therefore, be considered an obligated and duty based action. Mrs S recalled, “It wasn’t even my decision. It was her own decision to carry a card” [Mrs S: 781-782]. The influence of this perception as a duty or a responsibility should not be underestimated. As mentioned, two respondents who initially refused due to concerns about the transplantation procedures, eventually donated in the knowledge this is what the deceased wanted. Arguably, the same obligatory element applies if there was previous discussion in the family regarding donation (n=9 of 15):

MR J: No problems with it all. As I say it was my mum’s wishes so if I went against it I’d probably feel worse, not doing it would have been against her wishes, but this was what she expressly said she wanted to do [661 - 663].

Mr F: It was what she wanted. That was the size of it. I was not for it. I'd said to her many times that I would tear the card [donor] and she said she would come back and haunt me [679-680].

The phrase, "it's what she wanted," appeared frequently in Mr F's transcript, with it being mentioned at least six times, a mechanism perhaps to justify the decision to donate in the face of his own negative beliefs about organ transplantation. Mrs C, who also initially refused, decided to donate because of her husband's intervention, reminding her their daughter had discussed it with them before her death, framing it in a "it's what s/he wanted" discourse.

Self-Interested Donation

In some cases, not only was the donation act an obligation to the deceased, but also, appeared to stem from self-interested reasons, such as the donor families' potential need:

It's such an appalling waste anyway not to do it. Isn't it? Mmm... I think the only thing that stopped me thinking no they're not doing this [taking organs] [...] was that his cousin was there. You know the blond that looked like him? And I thought, if he was lying there and David [son] was dead and he was going to die would I still say no? If he needed a liver transplant? Or a kidney? Could I say no? Of if David was lying there and he needed one would I say 'no he's not having one'? You can't do it [Miss A: 522 – 530].

Mr R: It's also, you know if the roles had been reversed and say Laura had been lying there, or whatever it is, kidney or liver, and we had got one from somebody else and Laura was fighting fit again, you know that's great. So we could easily have been on the other side of the fence [445-448].

If I was not too well I'd like to think somebody would help me [Mr B: 353 - 354].

Whether these comments imply obvious self-interest is unclear, as there are several possible interpretations of these comments. The first is, donation stems from a desire to cover the eventuality of potential need. Yet, the likelihood of donor families being in a similar situation to the recipient, is neither desirable nor likely. Such accounts, therefore, seem more about *imagining* what it would be like to be in the recipient's circumstances. Arguably, the rationale seems more about "what would it be like if that happened to me?" and, thus, there are elements of sympathy displayed here.

Reciprocated Donation: Emotional Benefit and Public Kudos

So far, elements of obligation and sympathy are evident in some accounts. A related issue is whether donation was undertaken with the expectation of reward. If so, what

form would a return take, given the anonymity principle built into the UK organ procurement system? An element of public *kudos*, an expression of social approval from others, was expressed. Questions were raised in the interviews about whom the donor family respondents told about donation, and what their reactions were (n=13).⁹⁵ Mrs M told, “everyone” [529] she knew about the donation, and their reactions were positive, with remarks such as, “I find that really remarkable, you know, what you and your family have actually done for other people, these people that you don’t know” [640]. This is not to suggest all respondents received positive feedback (n=3):

Mr D: And I’ll say, “when Margaret died we were asked to donate some of her organs and I said yeah” and they’re like “did you?” and “that’s very good of you” you know? And then they say, “I don’t know whether I would be able to do something like that” [313-317].

Further, fifteen respondents said they received some form of emotional benefit from knowing they had helped others and/or carried out the wishes of the deceased:

Mr. F: [...] Fractionally. Maybe more than that. In that I know that somebody somewhere has benefited. And the fact that I’ve done what Georgina wanted and carried out her wishes and that [...] but eh I don’t feel a big thing. But if I was inclined, if I was going to have that for myself, which I doubt very much whether I will, then I would feel more, looking forward to it going to somebody, as I know Georgina looked forward to it. So what I’m doing, or what I’ve done is help her to feel good about what was going to happen to her after she was dead. And I know that’s what she wanted and that’s it. That’s all I got out of it. And maybe that’s quite a lot [695 – 701].

Mrs C: I think that the fact that people have lived because of her, you know? I think that that is a very small consolation you know? If you can call it that. It is a very small consolation, but it is a consolation [692 – 698].

The emotional benefit was not felt to be comparable or a sufficient compensation for their loss. Two respondents recalled they had expected to receive a benefit from donating:

⁹⁵ Only one respondent was reticent about telling other members of the family about the donation. Initially, she suggested this was because “we were kind of the opinion that we didn’t know what they would be able to use” and, “it really wasn’t anything to do with these people anyway” [413]. It emerged Mrs K and her husband did not have a particularly close relationship with her husband’s brothers and she had not spoken to them during or after the donation. Yet although she had qualms about telling other members of the family she did tell close friends about the decision. Telling others seemed to be as much about how significant you feel people are around you and the strength of social bonds to them and not necessarily that of kinship ties.

GH: So you have received some kind of benefit, some kind of comfort. Was that something you expected?

Mrs R: Yes.

GH: Did you? In what way?

Mrs R: I don't know, I just knew that it would make me feel better.

Mr R: We knew that somebody would benefit. At least somebody would benefit and so would we by knowing that [538-544].

Six of the donor family respondents seemed to gain further satisfaction from the knowledge that organs went to young adults or children:

Mrs O: And there is one I would like to hear from, a young boy of 22 who got Andrew's heart. And I would love to hear how he's getting on.

GH: Why him?

Mrs O: Just because he's a young boy [374 - 377].

Mr D: Nah, if it was a youngster then as I say that would be good.

GH: Why's that?

MR D: Well I feel if it's a youngster and they've never had much of a life. As long as they value it and make something of it. I'm not saying that everybody would, maybe go to university or something like that [286-310].

Others appeared disappointed that the organs would not go to a younger recipient:

Perhaps it could have been made a bit clearer to me that they would have been the same age as Georgina. But thinking about it I should have known they would not have put a 53-year-old heart into a 22-year-old. It's got to wear out [Mr F: 566-569].

In this society a child's death is particularly emotive, viewed as a life cut unjustly short. Donating to a child, therefore, appears to be particularly desirable due to the potential future, and additional years of life the child would receive.

Was the Gift a Good One?

The emotional benefit the family received from knowing they might have alleviated another's suffering sometimes led to a desire to find out how the recipient was getting on.

One donor family respondent had initiated contact with a recipient:

Mr B: Just basically how was he keeping with his new heart and how his family, how his wife and family are getting on and em, how's things, has it been a bit easier now. And I can't remember to be quite honest with you. Just generally being nosy. How's he getting on.

GH: And do you think that was important to know?

Mr B: Yes.

GH: Why?

Mr B: I just was, it was always at the back of my mind as I say, and em, I thought that if I never get that letter written to the guy I'll never find out and it will always haunt me for years and years.

GH: Why was that do you think?

Mr B: It's just me. I think it's just me. Probably. Just thinking that he's got Linda's heart and I just wonder how he's getting on and as I say, it would always be there, I would still be thinking about it. On a daily basis, it's wearing my mind away here [504-521].

For donor families, this account highlights a desire to know the donation was beneficial to the recipient. This was also weighed up against not wanting to know if the transplant had been unsuccessful. For example, Mr X comments, "why should I worry? Why should I concern myself with 'oh God, someone else is dead?'" [228]. Mrs K was more concerned to know that, "it's not been a waste" [515]. This was a sentiment shared by Mrs M, who also felt that she would rather not know if the transplant had not worked. Equally, Mr D was anxious about whether the recipient was also worthy and grateful for the gift:

Mr D: Well obviously you think because you don't know anything. You don't know them, you don't know their lifestyle, so as long as they are making full use that's the only thing and I hope that they appreciate what they are getting. Apart from that [pause] I wouldn't like to know more. As I said before it could be somebody who is a bit of a waster and didn't appreciate it and that would really hurt you, so I think you're better not knowing. You're giving them the chance and really that's enough [386-391].

Organ Donation – Bodily Immorality?

Other respondents were interested in the whereabouts of the organs and the age of the recipient. Miss A, for example, asked the transplant co-ordinator whether her son's organs could stay in the area (while simultaneously recognising that this could not be done and allocation was based on HLA matching and waiting lists throughout the UK). What she wanted was to:

... Try here first. Because I don't want ever to go to Bristol thinking somebody is walking about here with David's heart. I hate Bristol. I'm not going back there. You know? I don't want that feeling. Cos it would be as though, "*well where is he?*" [Her son]" [233-235, emphasis added].

For this mother, it would appear her son is co-existent with the location of his organs. Donating his body parts implies that the body/person as whole persists. Indeed, other facets of the person, for example, their national identity, appeared significant. Two respondents mentioned a desire for the organs to stay in Scotland:

It was her liver or something but it did go to like an 18-year-old in Ayrshire I can remember that and thinking that "*I'm glad it stayed in Scotland*" and her heart went to somebody down South. One of her other kidneys, I think that went somewhere, *but not too far down South*. Mid kind of way [Mrs M: 620-623, emphasis added].

Clearly evident, is a strong emotional attachment to the organs and an interest in their location. This seems to be an indication that organ donation is not simply a case of donating body parts. Some donor family respondents suggested that personal characteristics, if not the person, persist post-donation. One respondent articulated a fear about a confusion of personal identity for the recipients, and a suggestion that personal characteristics were transferred from donor to recipient:

Mrs S: But eh, I think that some people would want to know too much about the donor and then say, well if the donor, was a drunkard, well maybe I'll end up the drunkard.

GH: But I mean, what you're saying ...

Mrs S: I mean taking on the personality. I don't think that's a good thing. I think the less we know is better than knowing too much [78-792].

It is not clear how this transference of personal characteristics occurs. At a fundamental level, it assumes that post-death, the person is inextricably linked with their body and parts, though this did not seem to be a widespread belief in the sample - Mrs S was the only respondent to suggest organs could carry personal vestiges of the deceased. Researchers have argued donor family respondents donate due to "bodily immortality," (Fulton *et al.* 1987) in a sense, not only prolonging the recipient's life, but also that of the deceased. Did donor families believe that the deceased's life would be prolonged through donation? Do organs carry with them vestiges of the person? Mrs S was the only respondent whose account substantiated the "body immortality" argument, when post-donation, parts of the deceased may "live on":

GH: How do you feel now about the decision to donate her organs?

Mrs S: Well I feel that there is a little bit of her out there somewhere.

GH: In what way?

Mrs S: Well somebody is being able to use it. You know? She's not gone completely gone [934-941].

Through donating, her niece continued to be present to her and she was still about "somewhere." In the majority of other cases (n=3) there was an explicit statement that, "it was not the person" only their organs continuing to exist:

Mr E: No it occurred to me a week later that was where his body went. But parts of him that were very much alive are still alive. I think eh, I felt that that was em, a strong consoling moment for me.

GH: That he was still kind of alive?

Mrs E: No, his organs [304-308].

Mrs R: I just thought yeah you know that there is part of her somewhere around. Just working away somewhere, I mean I know it's not her, but it is part of her [441].

The above quotes suggest it is a part of the deceased, not the deceased themselves, continuing to persist. Significantly, however, none of these statements bore any relationship to the decision to donate, rather it was said to be an unexpected outcome.

Donor Family's Denial of Reciprocation

The argument proposed by some researchers, that feelings about bodily immortality can be frustrated by the lack of information about the recipients, was also unsubstantiated (Bartucci and Seller 1986). By the time they were interviewed, eighteen donor relatives had received a letter from the transplant unit giving information about the age, sex and location of recipients.⁹⁶ In general, it was felt the information provided about the recipient, the location of the organs, sex and age was sufficient. But fifteen relatives said, though they would not initiate contact by writing to the recipients, they would not mind if the recipients contacted them.⁹⁷ Mrs M described it, as not wanting the recipients to feel "beholden" to her, "cos they have to get on with their life you know? Without having to drag it all back up again" [439]. Mr J expressed similar concerns:

GH: Just going back there, you wouldn't initiate contact with the recipient?

Mr J: No cos in that situation you almost feel like, that you were almost putting an onus on them, it's a case of 'oh right we've suffered grief, you've got this organ from us' and I wouldn't want a situation that somebody would feel that they owe you something. It's an awkward situation altogether cos they are going to feel that through your grief they received, you know a gift. I wouldn't want a situation where I would expect someone to say thank you [476-483].

There was recognition by donor families of the tension organ transplantation creates. Cadaveric organ donation rests on a double edged sword; benefit to one individual can only be made at the expense of another's loss. Thus, they recognised the recipient may

⁹⁶ The organ procurement system negotiates contact between donor relatives and recipient, the transplant co-ordinators playing a gate-keeping role. The reactions to the letter were uniformly the same with expressions such as "I really liked that. I appreciated it" (Mr F: 572), "not heartening but along those kind of lines" (Mrs M: 631) and "it was good" (Mr. A: 189). Although it could also cause distress, "it upset me very quickly and very briefly. It upset me very quickly cos obviously it was a case of that it reminded me of everything that had happened. But that was fleeting" [Mr J: 416-421].

experience some degree of ambivalence, insofar as they had gained from another's death. Additionally, the comment above implies the donor next-of-kin seemed wary of contact, due to a belief the recipient would be made to feel they had to reciprocate in some manner for the donation.

Elements of Altruism in Donor Family Accounts

Findings suggest elements of obligation and sympathy play a part in deciding to donate organs. There is also an unemotional benefit when the organs have been donated through the expression of social approval or knowing that another's life might have been saved. Donation mostly occurred without the *expectation* of reward, and so was not based on the principles of exchange, defined as a lateral transaction. A return was not offered or given by the recipient, rather the families were aware that "that it was a free unconditional gift. It was done and that was it and we owe the people who received nothing. And they owe us nothing" [Mrs E: 597-8]. The gift, it was hoped, would be a "good one" and would be given to where it could do the most benefit, that is, to the young.

So discussion turns to other related elements of non-reciprocated gifting and how the family make the decision to donate in the absence of an obligation to donate. In the absence of a donor card and/or previous discussion, relatives framed the decision to donate, in terms of the characteristics of the living person, imputing charitable tendencies to the deceased. For example, to Mrs K "it wasn't a conscious thing. You know he hadn't said 'use my organs.' But just, you know someone you've lived with them for so many years" [485-487]. Despite her son initially refusing to donate his father's organs, Mrs O suggested to him his father, "wasn't a selfish person. He would help you [her son] so he was helping other people" [474- 476]. Her son subsequently agreed. Thus, through employing their intimate knowledge of the deceased, relatives can frame the decision to donate in terms of "*well although s/he did not express their wishes regarding donation, from what we know of the deceased whilst they were alive, that's what they would have wanted.*" So, it is still the deceased who informs the donation act, but only in a passive role as a reference point to decision making. Basically, the deceased continues to exert an influence on the present social world. This finding will be returned to at the end of the chapter to discuss further aspects of this phenomenon. For the moment, it appears the deceased's actual or perceived charitable characteristics inform the donation decision.

⁹⁷ The hypothetical suggestion of a face-to-face meeting between donor and recipient met with similar ambivalent responses. Six of thirteen respondents asked, willing to meet the recipient, only would do so if initiated by the recipient.

Recognition of Need

At least half of the donor families said they also recognised and wanted to alleviate the suffering of another:

Just to help others. That's all. Just to help others. To give them a chance in life. They are so ill and they might never get another chance again [Mr B: 657-658].

Oh yes. My son immediately said, he said I think of another family sitting here similar to the way we are just now, looking and hoping for a donor [Mrs K: 481 – 485].

Mr X: I was just thinking I could help someone. The recipients and the families. Sometimes more so the families.

GH: And why's that?

Mr X: Mmm...cos sometimes its the families who suffer more than the person. Like only one person has got a bad heart, but you've got children and grandchildren and they're all gonna go "he's in bed and can't move." You know what I mean? It affects him but it affects absolutely everybody else in other ways [232–238].

Arguably, empathic concern is significant, and the ability to mobilise this concern was demonstrated by the majority of donor family respondents, who imagined what it was like to be in the recipient's position. Donation was about intervening, and providing an immediate resolution to someone else's distressing situation, and not necessarily about the possibility of gain or return from the recipient. At least half of the respondents had thought about the recipients at the time of donation, and all donor relatives asked, stated they had thought about them post-donation, some while still acutely aware of their own loss:

Mr F: Eh aye every now and again I would wonder now and again how they're getting on but it was only a fleeting thing. If I'm being honest I was more sorry for myself than pleased for them. That's the way it goes. You can't have half your life torn away and think about other people. [Crying] That's the way it is [595 – 598].

As did Mr X who still thought about them occasionally:

Mr X: Just now and again. Not a morbid fascination or anything. I've seen the films where they transplant the heart into some women and then they fall in love all over again. Dearie me no [laugh]. No I've never actually thought it like that. I just think, I wonder how they're getting on or I wonder if they're still alive [219–221].

SUPPORT FOR THE PRESENT VOLUNTARY SYSTEM: ATTITUDES TO FINANCIAL INCENTIVES/PRESUMED CONSENT

Because the UK organ procurement is based on the principle of anonymity, the donor family respondents do not receive any reward from the recipient, apart from the element of self-induced emotional comfort, gained from coming to the aid of another. Nevertheless, would the respondents have liked to receive some form of tangible gain from donation? Indeed, given their pro-donation beliefs would they have minded if the organs had simply been taken? Dependent on answers, this was interpreted as either support for the present system, based on non-reciprocal gifting, or alternatively, for the introduction of financial incentives or presumed consent.⁹⁸

The reaction to the introduction of financial incentives was unambiguous – sixteen of seventeen donor relatives asked were vehemently opposed.⁹⁹ Common statements were it was, “immoral,” “it would be like selling” and, “money shouldn’t come into it.” Others seemed more emotional about the issue:

GH: There’s another system where relatives are offered some form of compensation as eh..

Mr X: What like money? That’s sick

GH: How is that sick?

Mr X: That’s just no. I wouldn’t even think about that one [330-333].

Mr F: For me personally that would have stopped me donating.

GH: Really?

Mr F: For people perhaps who are in financial difficulties eh I don’t even know if that’s for them. They’ll always feel that they’ve sold their parts for, just to just to, no I don’t think. I can see people wanting to give the best funeral that they could afford. It’s a difficult thing. That’s a very difficult question. I wouldn’t want to feel, eh later on, I would think that I donated Georgina’s organs to save myself getting into debt. And I’d rather be in debt than have that thought. Does that make sense to you? [740 – 750].

In contrast to negative reactions about financial incentives, responses to the introduction of presumed consent were mixed, with ten respondents in favour of presumed consent, and eight against. Those in favour of presumed consent, however, found a “hard” version unacceptable, and thought relatives’ objections should also be taken into account:

⁹⁸ Their opinions were felt to be of interest because donor relatives had experience of the present voluntary donation system. They are, therefore, uniquely positioned to assess the current system’s strengths and weaknesses, and gauge how they would have felt about others.

⁹⁹ Some, initially assumed financial incentives would affect living donors, and drew parallels with the American commercial blood system. When it was pointed out financial reimbursement would be offered after death, the consensus remained unchanged, finding the option, generally, distasteful.

GH: If the relatives objected should they still take them?

Mr B: If they objected? I would say no, I would say leave it alone, if they don't want them to do it, leave it. That's fine, shouldn't pressurise them [700-703].

Those that rejected presumed consent had strong beliefs about the importance of the next-of-kin's rights to give:

Mr F: They're stealing people's bodies [...] I think to be honest whoever the next of kin is needs to make that decision. If there's no next-of-kin then, aye, assume consent.

GH: Why do you think it's important for the next-of-kin?

Mr F: Cos they're left behind [728-739].

Mr U: It takes away the person's right to give.

Mrs C: I think it's important because people should have the right to be, that's everybody's human right to say, this is what I want [711].

Those against presumed consent, stressed the importance of an individual's right to give, as opposed to the State's right to take. Equally, others supported the present gifting system, suggesting donor cards should be in more accessible places, such as supermarkets and doctor's surgeries. Further suggestions were an increase in publicity to overcome public apathy (Mrs M), and introducing the topic of organ donation in a school's curriculum (Mrs E). Significantly, views about presumed consent were strongly correlated with views of the body. All respondents that did not restrict organs were in favour of presumed consent, and four of the five that did qualify organs to be donated, were against.

Organ Donation - Altruism in Action?

It was consistently suggested by the donor families that:

- they had thought about others when making the decision to donate,
- they did not want a return for donation,
- they did not want to receive a financial gain,
- they did not want to meet the recipient in case they felt they had to reciprocate,
- those against presumed consent legislation emphasised a "right to give,"
- there was, mostly, no expectation of reward from the gift.

From these accounts it is clear that organ donation is governed by the norm of beneficence and not necessarily that of reciprocity (Gouldner 1973). The gift is not given

for reward or gain, and stress is placed on meeting the need of others. Then, it is an action that takes place within the sphere of the moral economy, where the deed is undertaken for others, and not out of self-interest. Obligation and duty played important roles, as did sympathy and imagining how it would feel to be the recipient.

Continuing Social Existence

At the beginning of this chapter, I argued the relatives' accounts implied they could, and did, pronounce social death prior to the announcement of death defined by medical means. Yet, if a person can be pronounced socially dead, could a dead person continue to socially persist? If the physical manifestation of the person is destroyed, can social mechanisms and devices by the bereaved keep their representation alive? Organ transplantation depends on a separatist view of personal and bodily identity after death. The newly dead body can be construed as the person and mutilation is, therefore, abhorrent. Yet the majority of respondents did not believe the person persisted in the donated organs. Neither did they suggest that the body was needed in the after-life or, indeed, that there was an after-life. The connection between what happens to the body in the after-life, and the decision to donate, arose spontaneously in some of the interviews. Eight respondents articulated such comments:

GH: Would you donate your organs?

Mr D: [long pause] Eh I suppose once you're dead, you're dead. Eh it's not going to hurt you [346-348].

Mrs O: He couldn't use them anymore so why burn them? [474 - 476].

Mrs S: No. As far as I'm concerned once you're dead that's you, that is, what you lived in when you were here. If there is such a thing as an after-life you're not needing that. Do you? And if someone else could use it why not? [603-606].

So, although the newly dead body may still be viewed as a representation of the person, this belief does not necessarily persist in views on what happens to the person or the body, in the after-life. This seemed unrelated to affiliation with any institutional religious denomination or how the body was to be disposed of (either through burial or cremation).

Once the dead body is destroyed, it no longer serves as a representation of the person. This does not mean the person dies – they can still socially exist in their previous, social world. During a wind down period at the end of the interview, the topic turned to how the respondent was coping with their bereavement. This was also a time when respondents spoke about their memories of the deceased, accompanied by the showing of

photographs. As one would expect these accounts were particularly moving, yet they also had a vividness and intensity which hinted these discussions were more than simple reminiscing. Rather, it became clear, especially in conversations with respondents in the first year of bereavement, the deceased's past existence and the relationship between deceased and bereaved continued to be experienced. In other words, the deceased was not easily excluded from the life of the living. Mr F particularly outlined strategies to try and minimise this:

Mr F: What I've tried to do is cut down on things that spark me off.

GH: Have you?

Mr F: Aye. That's why I've changed the room.

GH: Why?

Mr F: Cos I think about her enough as it is. I don't need any // I know what you're saying. I'm not trying to cut her out my life. It's just the fact that // [crying] there won't be an hour goes by that I don't think about her [494 – 499].

He explained what he wanted to do was to, "spend a bit time with her when I'm not getting emotional" [515]. Another reason why he changed the furniture round was he could still feel her presence in the house. Not in a supernatural manner, but "it's just the fact that I've seen her there that often. That if I look in the room I almost think she's still there. Which is one of the reasons why I shifted the chairs round, cos I kept looking at that chair // almost expecting to see her there" [Mr F: 526–529]. Others also suggested the deceased's presence could almost be tangibly felt. Occasionally this could be comforting, sometimes distressing:

Mrs G: It has been quite hard. I do get on with my life and I know that he is close to me and I know he helps me, and I believe that we will meet again and I know that keeps me going [508–509].

Mrs O: Well these are the stages that you go through. It could be five or ten years before it hits you. Do I feel close to him? Well he's here. He's here [616–617].

Mrs E: But sometimes I can feel him around. Sometimes it brings a terrible darkness.

GH: It's not comforting?

Mrs E: No, no it's dark, very black and dark. Em, I think if I could let go of him, and really accept that he is dead and then move on. I think I would get him around me a lot more. I think he's going 'mum come on'" [Mrs E and Mr E: 728–733].

One respondent gave a time limit for how long the deceased was "around." "They are always there for seven years when you lose someone and then after seven years they fade. But they are still there, but not on a daily basis" [Mr B: 743–747]. The deceased's continuing social presence appeared to be an almost taken-for-granted assumption and

though they were obviously physically dead, they continued to be “close” to the bereaved through an emotional and/or cognitive medium:

Mr J: I'd start thinking, but just as I say, I am firmly of the belief that she is floating round in my head. Or at least the memory of her is, let's put it that way.

GH: In that sense, do you still feel close to her?

Mr J: Yeah. I still feel close to her. Somebody once said to me that “people are never dead as long as somebody remembers them.” And I would subscribe to that theory.

GH: Would you?

Mr J: Yeah. Yeah, as long as somebody remembers them. They might be physically dead, but they're not totally dead [Mr and Mrs J: 530 - 540].

Mrs S: I would put it that she's maybe not here, but she's in there [points to her heart] [376].

Or the deceased continues to be “alive” in others:

Mrs O: He'll always be alive. He's alive up here [points to head] but he's alive here as well [points to son]. As long as he's alive, then his dad will never die [608-613].

Conversations with the Deceased

The relationship between deceased and bereaved continued to persist in their previous social world, with the former playing a part in the ongoing life of the bereaved. This was similar to the way respondents framed the donation act, in terms of the donor's characteristics, e.g. “it's what s/he wanted,” and referred to their generosity during their lifetime as a reference point for donation. Such rationales could also be referred to in other contexts, especially if difficult decisions had to be made:

Mrs G: I just feel that Brian's still with me. And it's strange because, and yet I don't suppose it's strange [crying]. If I'm maybe concerned about something and I think ‘I really don't know what to do’ and ‘I've never made a decision about something like this before,’ I would chat to you Brian, and would think about it myself and then between us we'd come to something. It's difficult for me doing it on my own. You know? [225-235].

Mrs S: In a way she still is physically about. Although, I dunno, she's certainly still around. I know it's just in here [points to chest] or in here [points to head]. But she's certainly still around and gets talked to quite a bit [941-944].

Mrs S: Oh yes. If I get into a pickle I think ‘oh how the hell am I gonna do this, come on Caroline help me.’

GH: Do you really? Do you do that?

Mrs S: Uh-ah, and I do still expect Caroline to help me [367-371].

Mr. F: I still eh driving down from [place] see the hills and I'd say to myself, 'Georgina would have liked that.' Or something happens, I say, 'have to mind and tell Georgina about that.' If I can't find something I'll say, 'Georgina will know where it is.' Sometimes I'll talk as if she's still here. Mostly, I talk about her in the past. She's not really. She's not in the past.

GH: She's in the present?

Mr. F: [nods] [482-491].

Correlation between Nature of Past and Present Relationship

A correlation was found between the nature and length of the relationship with the deceased whilst still alive, and continuing social existence. Mrs M drew out the differences between how she felt about her sister, with whom there had been a certain amount of tension and conflict, and her mother, (note the tenses used in this quote): "Aye. I think you always think about her. But I think about my mother more. But I mean I had a sister as well. It's just that I'm closer to my mother" [emphasis added 784 – 786]. Miss A, and her maternal feelings towards her son, drew out the intensity with which, even though an individual has died, they can still remain a part of the bereaved. To her, "I've got him. He's part of me" [crying]. She explained, "He started off as part of me. And what's very evident is that I don't even have to share him with his father now" [745 – 747].

Do Dead People Die?

It is a truism to say dead people are dead. People die, at least in a corporeal manner. But their relationship with family and friends in the previous occupied social world may continue, at least on behalf of the living, in a very real and intense manner. Relationships do not just simply come to an end. The deceased continues to be thought of, talked to and their presence (at least in the early days of bereavement) can almost be felt. When decisions have to be made by the bereaved, they frame it in terms of what the deceased might have done, in an internal dialogue with them. Moreover, these continuing social bonds need no reference to religious axioms – this is a social phenomenon emphasising the persistence of a significant other, with a few respondents even placing a time limit on how long the deceased remains "around" – seven years. Respondents interviewed after three or four years, who had already moved on to new relationships, admitted to a continuing bond with the deceased:

GH: Do you still feel close to her?

Mr B: Oh definitely. I'll never lose her. It's like a bond. I mean, I'd known her since she was sixteen.

GH: So it's like a bond?

Mr B: Oh definitely [619-622].

These continuing ties were not so much a psychological mechanism to deny death, but part of a continuing relationship to the deceased, a relationship that could even be made known to others:

Mr E: He is absent in the sense that we are present to one another with our senses. With our intelligence. [Pause]. But just as you've met Lesley [his wife] oh and you've met me, but I will leave you shortly. There's a sense in which, because of my relationship to Lesley, you might never see me again, but you know, Lesley, Lesley conveys part of me, because of what we are to one another [433 - 440].

SUMMARY

These donor family accounts show that the main obstacles to donation were related to concerns about whether the donor was "really dead," and to fears about mutilation of the body. Though BSD was said to be understood, it appears cessation of heartbeat is still an important rite of passage determining death. It is an event discernible to both relatives and health professionals. Brain stem death remains in the medical sphere, and though relatives said they understood it, accepted it, and appeared to deal with the implication of the diagnosis, in a minority of cases, it caused high levels of distress. It was not an event accessible to them in the same way cessation of respiration is. With no sign of injury, the dead body offers no clues to these relatives, who are active in a search for a prognosis. So some pronounced social death simply by looking for "life" in the eyes, and gauging the temperature of the body.

Just as there were concerns about death, there were also concerns about the organ donation procedures, interpreted as transgressing the identity and integrity of the deceased. Such fears are historically rooted and have been well documented by Richardson (1988), though an explanation for why these beliefs persist in the modern era rests on embodied personhood residing in the dead body. This explains why some groups, e.g. parents, especially mothers, seemed more susceptible to such concerns. I have argued that, this is because the dead body continues to represent the person, and as such, is imbued with an emotional and cultural significance. Such concerns were linked to continuing social bonds with the deceased, based on a perception of the dead body as

the person. Such beliefs regarding mutilation also applied to post-mortems, to expressions of sympathy towards parents involved in the Alder Hey episode and to why donation would be refused in the future. In short, it's a matter of respect. Medical respondents were less likely to have fears about mutilation, less likely to restrict organs, more inclined to view the body as "just a body," and to approach health professionals with an offer to donate. For them, organ transplantation does not disrespect the body, though it is unclear why they do not think so. Perhaps it is due to a belief in medical progress and a clinical detachment that stresses the body is just a machine, and not the person.

Insofar as the dead body is attached with an emotional and cultural significance, so too are its parts, with almost a third of respondents refusing to donate the deceased's eyes. This refusal revolved around three beliefs: concerns about the cosmetic repercussions of organ removal, symbolism attached to the eyes as the "windows of the soul," and a perception that sight may be required in the after-life.

However, such an integrated view of bodily and personal identity has to cease at some point for donation to occur. Organ transplantation is dependent on a view of the body that is not needed in an after-life (should one hold a view it exists). Then, when you're dead, you're dead and no physical remnant is left in this life, nor needed in the next.

So why did donation occur? There was a strong pro-donation attitude in the sample for both deceased and respondent, and approximately half of respondents and donors had donor cards. In the presence of a donor card, the donation act was considered an *obligation* by relatives to carry out the deceased's wishes. It appears relatives' fears about death and mutilation were overcome by this obligation, stemming from the deceased's wishes, regarding what they wanted to happen to their body. Though most respondents said they had received some form of emotional *benefit* from knowing they had helped others and/or carried out the wishes of the deceased, they generally did not expect such a reward. Neither did it come directly from the recipient, nor was it comparable or equal to their loss. Donation was not an action undertaken in order to gain benefit or profit and Gouldner's (1970) norm of beneficence helps understand why individuals donate organs. It was a deed done for the sake of an unknown other, whose need could be imagined and, therefore, be made known. There was a recognition and a desire to alleviate the suffering of another's critical condition. Such actions can be located within a moral economy, where values such as charity and generosity

predominate. The organ procurement system is based on voluntary, anonymous and unreciprocated gifting, in other words, altruistic principles, yet this is not to be confused with the actual experiences and attitudes of donor families. Respondents drew on a variety of belief systems and articulated differing, though not contradictory, explanations for donation. For example, Mr B, whose wife had carried a donor card, also emphasised the importance of helping the recipient, and an expectation others might do the same for him. For him, donation was the result of a combination of obligation and empathy. It follows that, altruism as an explanation for why donor families donate is too simple and general, covering complex and differing reasons for donation.

Equally, “bodily immortality” as an explanation for donation is tenuous. For the most part, though respondents said parts of the person were still considered to be, “alive” or “around,” this did not appear to substantiate the “bodily immortality” proposition. The organs remained physically present, but in almost all cases, were not equated with the person. For the donor families, the continuing social existence of their relative appeared to be more important, and was unrelated to a continuing physical persistence of the deceased’s parts.

The next chapter turns to whether these donor families’ attitudes, experiences, and belief systems are similar to, or different from, non-donor families. This leads to an identification of factors potentially distinguishable as influential elements in refusal.

CHAPTER 8: PILOT STUDY OF NON - DONOR FAMILIES

Introduction

In this chapter, a summary of the non-donor family interviews is presented. As I mentioned in Chapter 6, the success in recruiting donor families, was not matched in the non-donor sample. Thirty four letters were sent to non-donor families with fourteen responding. Seven, initially, agreed to take part (20% agreement rate), although for various reasons discussed in Chapter 6, only three interviews were conducted. Four respondents were present at interviews, however. Due to the small size of this sample, these interviews are considered a pilot study for further research, as opposed to one where conclusions can be confidently stated. The emphasis is on the exploratory nature of the interviews, with an investigation of non-donor family beliefs, attitudes and experiences considered significant, given the lack of research in this area. Though this preliminary data may be impressionistic, comparisons will be drawn with the donor family findings outlined in Chapter 7. This enables an exploration of whether there are any differences or similarities between donor and non-donor relative accounts, and the findings can be compared with other studies into relatives' refusal (for example, BACCN/UKTCA 1995, Tymstra *et al.* 1992, Dejong *et al.* 1998). The same areas of investigation are considered relevant: cultural beliefs about death and the dead body, support and communication by health professionals, inter-family dynamics and beliefs about the value of organ donation. As with the donor family accounts, there are also gaps in knowledge regarding events, and this is exacerbated by the sensitive nature of questioning regarding the decision not to donate the organs. As with donor families, pseudonyms have been employed to maintain anonymity and protect confidentiality.

The structure of this chapter follows a similar logic to the donor family findings. First, demographic information is offered for context, followed by an examination of the impact of the hospital environment, and health professional communication on matters such as BSD. Attention will then turn to the reasons non-donor families gave for their refusal, including an overview of whether they had knowledge of the deceased's wishes, their own and their families' beliefs about the status of the body, and the specific value of organ donation.

Non Donor Family Demographics

The non-donor families were on average a white, middle-aged cohort (though ages ranged from 25 to 70) with two respondents having some form of further education. Only one of the non-donor relatives affiliated themselves with a particular religion and said they attended Church regularly. Of the others, two admitted the death of their next-of-kin caused a deterioration in their own religious beliefs:

Mrs Q: I think it was kind of the timing. I was kind of religious, you know one of these lapsed religious, and I had always been brought up in the Church and that and after Jennifer’s death. That was it. As far as I was concerned; no God [77-79].

Table 19 gives demographic information of both the deceased and family members interviewed:

Table 19 - Demographics of Deceased and Non-Donor Family Respondents

SEX OF DECEASED	AGE OF DECEASED	YEAR OF DEATH	CAUSE OF DEATH	RESPONDENT POST-SCHOOL EDUCATION	DURATION BETWEEN RESPONDENT INTERVIEW AND RELATIVE’S DEATH	RELATIONSHIP TO DECEASED
MALE	70	2000	ANEURYSM	NO	1 YEAR 6 MONTHS	HUSBAND, MRS V
FEMALE	18	1998	CAR ACCIDENT	YES	4 YEARS	DAUGHTER/ SISTER, MRS AND MISS Q
MALE	20	1999	CAR ACCIDENT	NO	3 YEARS 6 MONTHS	SON, MRS P

The age cohort of the deceased varied widely, with two potential donors under the age of 21, and the other over 70 years. Unlike the donors in the previous chapter, these deaths were mainly due to car accidents, with only one stemming from an aneurysm.

Impact of hospital environment

As with the donor respondents, most of the respondents’ next-of-kin were taken to the nearest local hospital. Issues arose regarding care at the local hospital for one of the respondents. This reiterates findings in Chapter 7 that concerns about care and support are more likely to occur at local units. Mrs V was concerned her husband, “was left lying out in a corridor, you know, it was a shame” [110-112]. She suggested it was a “mistake” a room had not been set aside for her to be with her husband when he was first admitted

[145]. It also emerges that information regarding the potential donor's condition was provided at this early stage, though some relatives found it difficult to comprehend:

Mrs P: Yes. I did switch off a little bit when they started talking about brains and that. I was more concerned about his spine to be honest with you cos I thought there's nothing wrong with him [147-152].

None of the non-donor families reported any concerns about why their relative was transferred to the main neurological centre. Rather, it was taken for granted, transference was undertaken for specialist treatment. This may be due to the fact none of the relatives carried donor cards (the effects this had on non-donation will be returned to later in this chapter).

All respondents commented on the lack of facilities at the main neurological centre, "I don't think the facilities are good, like there was no place even to get coffee [Mrs Q: 190-192]. Others were concerned with the hospital's general condition:

Mrs P: But I was shocked at the state of the [hospital] to be quite honest. I was shocked at how dirty; oh I couldn't believe it [160-168].

Mrs V: Well to be truthful, I'd been there before with my niece and I'd been several times but I must admit neuro-surgical, at that point, was falling to bits. There was scaffolding outside, and this ghastly room with the paper peeling off it and a couple of pictures and I remember sort of saying that we should donate a couple of pictures to the [place] [laughing] [181-186].

SOCIAL AND MEDICAL DEATH

Ventilator

Once transferred to the main neurological centre, the patient was attached to a ventilator for further specialist care. In this sample issues arose regarding the length of time the patient spent on it. Mrs P attended her son's bedside for nine days after his accident, causing her a high degree of anxiety, resulting in eventual exhaustion and frustration.¹⁰⁰ "And I thought, 'why are they doing this?' 'Why are they keeping him alive?' and I mean, it was the [pause] Thursday he had the accident. And it was the next Saturday before they switched the machine off" [198-205]. Concern and tension became heightened in Mrs P's family, when the decision to turn the ventilator off was eventually taken:

¹⁰⁰ In contrast to Mrs and Miss Q, and Mrs V, whose experiences in intensive care lasted approximately 24 hours. Nine days, although perceived as excessive by Mrs P, is not unusual when compared to the time period for donor families that ranged from approximately 10 hours to 10 days.

Mrs P: But my younger daughter didn't want the ventilator switched off even though he was brain stem dead. She did not want him to switch the ventilator off. She thought if they could keep him going, even five years, somebody somewhere would find something to fix him cos they are always finding new things. [...] She got quite annoyed with me. But I couldn't take it anymore and I knew he was dead [302 - 340].

In contrast to Mrs P, who felt her son was maintained on the ventilator for too long, Mrs Q suggested her daughter was not maintained on the ventilator for long enough. When asked whether she had had any general regrets about events, like Mrs P's daughters, she also found the decision to switch the ventilator off regrettable:

Mrs Q: If I was to think about only in an intellectual, only in that way, I would then say she was brain stem dead and nothing would have happened. But this is not an intellectual way. This is a mother who had to make a decision to turn off the machine that ended her daughter's life, and I made that decision too soon. I don't know. I don't know whether to say I had to make it, I don't know who's to blame there, but / Em, and so I live with it. Or didn't live with it, is probably nearer the truth. Em, so I really felt that I made the wrong decision there. But it was not one of the options I was given at the time. It was, "it's time to switch it off," but I think as soon as I got home, I regretted it [577-580].

Mrs Q and her family said they were not given an option in delaying switching the ventilator off, so to her "she ended her daughter's life," despite claiming she knew her daughter was brain stem dead. Thus maintenance on the ventilator for what was perceived as too long can lead to exhaustion and frustration, whereas switching it off too soon, can also lead to high levels of distress and tension in the family.

Appearance of Donor

As in the case of donor relatives, the non-donor family respondents said they also knew the ventilator was aiding respiration:

Mrs Q: No I personally would have them put anything they like in if it was going to save her life. Really to be honest with you. I did realise that she wasn't going to be able to function on her own, she needed help. So it wasn't a problem [252-258].

The same issues regarding a lack of external, obvious injury to the body arose, however (n=3):

Miss Q: I mean the numbers fluctuated. It was just so hard because she did not have any external injuries. She had a wee bruise on her forehead, a wee cut or something and that was it. I mean nothing else. So that was quite hard [242-244].

Mrs P: He was obviously very heavily sedated and he had a neck brace on cos they thought he had done something to his spine. And they did tell me that he had a head injury but I couldn't see how he had a head injury, as there was not a mark on him. Not a mark [132-134].

Clearly, the next-of-kin's body gives no indication of the seriousness of their condition, and like donor families, non-donor relatives also turned to the intensive care technology for signs. Relatives in an intensive care environment are active agents, searching for indications of a possible recovery.¹⁰¹

Miss Q: They were measuring the pressure cos I remember sitting and willing the numbers to come down cos she had diffuse haemorrhages. It wasn't one that they could operate on so they were basically measuring the pressure.

Mrs Q: And someone explained that to us earlier on and why that was there and it released the pressure. Cos I had thought well OK the pressure isn't coming down operate. Em and then another young doctor came later on to give us the news that really there was nothing they could do [221-232].

Mrs P: They had this machine and it showed you the pressure in the brain. And it had numbers and it went up and down, and then they would release the pressure and the number would go down. [...] And we knew that, and every one of us would be going in and, 'it's at number ten,' then somebody else, 'it's at number twenty-two' that's bad.

Mrs P: A male nurse, it was only the two that cared for him. One of them had explained everything and these were things that we were grasping. This male nurse must have cottoned on to what we were looking at, and he said to me, 'these are for us, these are not for you. I know you have to know what they are, but don't build your hopes up about this' [226-245].

THE ROLE OF HEALTH PROFESSIONAL COMMUNICATION

Brain Stem Death and Tests

Thus relatives were actively engaging in their own assessment of a potential outcome. Like the donor family sample, health professionals provided information regarding the patient's condition. All respondents said the term, brain stem death, had been mentioned to them. Like the donor families, most respondents in this pilot sample did not know what the BSD tests involved. However, their recollections suggest an explanation was

¹⁰¹ However the high level of technology also produced a certain alienation from the environment and a fear of physically touching their relative [MRS Q: 777-778].

offered, that is, two different doctors were required, and only after the conduct of the tests, was BSD confirmed. The diagnosis was said to be understood, yet unlike a few of the donor families, these relatives stated they did not require any more time. Most said they felt the explanation given was sufficient, and there were no associated problems:

GH: Did you feel that the health professionals took time to help you understand?
 Mrs V: Oh yes.
 GH: And were other members of the family OK with the diagnosis?
 MRS V: Yes, uh-ah.
 GH: Was there anything difficult about it?
 MRS V: Not really, no. They were very, very good in explaining it [220-225].

Nevertheless, although no difficulties were mentioned about an understanding of BSD, for Mrs P further anxiety was caused by a delay between the two tests:

MRS P: I was quite, cos Colin had been there for nine days, it must have been, I mean I know they are busy. But I know for a fact the ward sister didn't like the delay. She did not like this delay. She kept apologising, but it wasn't her fault. And you weren't talking an hour, a long day waiting on another doctor [274-296].

Other studies (Dejong *et al.* 1992, Tymstra *et al.* 1998) emphasised non-donor families are more likely than donor relatives, to have difficulties reaching an understanding of brain stem death. This was not the case in these interviews. As with donor relatives, non-donor families in this sample did understand the diagnosis of BSD, due to the provision of clear communication by health professionals.

Social Death

In Chapter 7, it was shown communication by health professionals led to the majority of donor family respondents understanding BSD, and enabled them to reach their own conclusions regarding the next-of-kin's prognosis, even before it was confirmed. The phenomenon of "social death," where relatives pronounced death prior to the confirmation of medical death (as determined by BSD tests), was based on health professional communication. Indeed, most non-donor family respondents stated they were happy with the information and support they had received from health professionals (n=2). Yet only one of the non-donor family respondents pronounced social death:

Mrs P: But I knew the outcome. But as I told my older sister, she was there at the time, and she was like ‘no, no.’ I said, ‘I’m not getting him home. I know I’m not getting him home’” [187-189].¹⁰²

The only non-donor respondent to pronounce social death said it was made clear to her what the role of clinical staff was, “that they weren’t there to heal. That they were only there to nurse him. They made that quite plain” [Mrs P: 194-195]. Others suggested they “never gave up hope” that things would improve:

Miss Q: I don’t think we ever gave up hope.

Mrs Q: yes, although we knew it was serious.

Miss Q: I don’t know why you don’t give up. I remember feeling like I couldn’t believe it, this can’t be happening [237–240].

Tensions In Interactions with Health Professionals

Though the care the patient received was unanimously thought to be exemplary:

Mrs P: I hadn’t seen anything like this. I mean I would never, the care he got was very good. It was excellent. They were there and talking to him all the time. I thought that was great cos I meant there was no way, he, but they didn’t seem to bother they just talked to him like normal and did things for him [Mrs P: 163-165].

Nonetheless, Mrs Q and her daughter felt the care they received as a family was lacking:

Mrs Q: For Jennifer I think probably the best care available. Em, I think that perhaps a little bit more for people who are left sitting. Nurses sort of came in and out, and yes you could go in now, you have to go out now, you can go back in. We were left sitting, not knowing why we were coming out.

Miss Q: And they never told you what they were doing really.

Mrs Q: I mean if it was only checking the machine I don’t think we should have been asked to go out. To be honest with you.

Miss Q: Even just moving her on the bed for bedsores.

[...]

So I think the care that we received as a family, that as a family it was lacking [331-344].

Though speculative, it seems the relatives’ optimism and an expectation of recovery, in conjunction with a perceived lack of care and information, leads to social death not being pronounced. For most of the families in this sample, there was no anticipation of death and, therefore, the pronouncement of BSD was unexpected;¹⁰³ whereas for the majority

¹⁰² This is not to suggest when death was confirmed it was not met with shock, “numb. Completely and utterly. Even though I knew there was no hope. I had known for two or three days. But because they told me. Shocked.” [Mrs P: 269-271].

¹⁰³ Compared to the donor family respondents, no mention was made of health professionals using “tacit feeling.”

of donor families, death was gradually accepted as inevitable, and this was based on dialogue and communication with health professionals.

The Need to Be With Their Relative

The non-donor family statements highlight a “double burden” for health professionals. Patient care can be made at the expense of family care. A conflict between care for the patient and care for the family, is highlighted when relatives need to be physically close to their next-of-kin. Tension was created when clinical staff sought pragmatic means of being able to reach the patient quickly in case of emergency situations. The strength of the non-donor family respondents’ desire for physical contact caused tension when health professionals tried to limit the number of people at the bedside. Mrs Q related:

Miss Q: We certainly wouldn’t have got as much time with her. I mean limiting it to two people...

Mrs Q: I mean I think two to a bed, I think, unless there is some very, very good reason for it.

Miss Q: I think immediate family should be allowed. I can’t see how they can say one member of the family is more important, everyone just has as much right [793 – 796].

Like the mothers in the donor family sample, the emphasis is on a desire to support and protect your child. Mrs Q explained:

Mrs Q: If any of my children are ill, your instinct is to be with your child. You don’t want to leave. It doesn’t matter even if you’re just there to hold a hand or something you are there and you have a physical contact with your child. That’s what you need. You need the physical contact, you need to see, to touch them, even if they don’t really know you’re there [349-358].

Mrs P also suggested the desire to be with her son led to exhaustion, as she remained by his bed-side for nine days [156-158]. Therefore, a strong theme arising from both donor and non-donor family interviews, was the continuation of relationships, especially the protective role of parents. As with mothers in the donor sample, who stated regret at not being present when the ventilator was removed, the mothers in this sample also stated a desire to be present at that point:

Mrs Q: When they told me about the ventilator coming off and I said, “I wanted to be there.” It wasn’t going to be done without me, and we all wanted to be there.

GH: So you were all there?

Miss Q: And then they took all the tubes out and we went back in [304-307].

There was no mention of concern at “not having a moment of death,” as was the case in the donor family sample.¹⁰⁴ Because donation did not occur, non-donor relatives could be present when respiratory support was removed, so there was a moment of death.

ROLE OF FAMILY DYNAMICS

Organ Request

Once death was pronounced, the family was usually approached with a request for organs. Three respondents suggested the request was made sensitively: “he did it quite nicely” [Mrs Q: 321]. They recalled they felt under no pressure (either through lack of time or by the health professionals), and the request was made in a private place. Only Mrs P had concerns about how the request was made:

GH: And had you ever met this consultant?

Mrs P: No. It was actually a doctor that was in theatre and he came to speak to me in his theatre clothes.

[...]

Mrs P: His hat on and his mask around here, which I didn’t like [274 - 296].

Just as the donor family sample thought it important transplant co-ordinators did not wear a uniform, and it was then found easier to speak to them, the comment above demonstrates the wearing of surgical clothing symbolises a barrier between the medics and the relatives.

Family Exclusion

As with the donor families, the legal next-of-kin was approached with the request for organs. If the deceased was a child, the parents were asked, and if the deceased had been married the remaining spouse was asked. Equally, in a normative sense, other family members accepted this was the case. Mrs V’s family, for example, did not interfere with what was perceived as her status in making the decision:

GH: What about your family?

Mrs V: No I didn’t. I decided to make that decision and nobody said anything.

GH: Why did you not want to discuss it with the family?

Mrs V: Well they were all there and they never said, and I had said, ‘no I don’t think so’ and they just accepted that [236– 263].

¹⁰⁴ Recall Mrs C, who said donating her daughter’s organs, meant she found it difficult to leave her in hospital still attached to the ventilator.

Family Inclusion

In contrast to Mrs V, who felt it only her decision to make, the influence of significant others was apparent in Mrs P's account of events. Mrs P's daughters had an important impact on the decision, reiterating the claim made in Chapter 7 that the influence of children was not merely symbolic:

GH: And what was your reaction?

Mrs P: 'No I don't think so.' His sisters they were no, they were hysterical. The nurses had to come and get them, they weren't doing this to Colin.

GH: And that was their immediate reaction?

Mrs P: They were like 'no.' I thought they shouldn't have asked me when they were there. Because, I think I would have still said no, but I did, I was so, you panic about them [305-311].

Though Mrs P suggests that she felt she should not have been asked in front of her daughters, this would not have made any alteration to her refusal. Rather, the request made in their presence had caused her additional concern, through anxiety about her daughters' grief.

REASONS FOR REFUSAL

This last section turns to identifying the factors that led to refusal. As shown in Chapter 7, donor families articulated concerns about death and the status of the dead body. However, these families were generally supportive of organ donation, and through the presence of a donor card, the decision to donate was perceived as an obligation to carry out the deceased's wishes.¹⁰⁵ The presence of the donor card and/or attributing charitable characteristics to the deceased, were important factors in overcoming initial refusals by the donor relatives.

In this sample, at least three of the four respondents also attributed charitable tendencies to the deceased, "I know he was the type of boy that would have liked to help other people," [Mrs P: 211]. And, "I would think that Jennifer that probably would have been the kind of child that would have said, you know 'OK let me help somebody'"[Mrs Q: 369-371].

¹⁰⁵ Indeed, despite difficulties in comparing these groups, as regards previous altruistic acts the respondents in this sample seemed equally as "altruistic" as their donor family counter-parts (and likewise, may be due to the ubiquity of socially desirable answers to this question). Three of the four said they either had done/or were involved in charitable activities. Mrs V for example, reported she delivered "meals on wheels" for 20 years and Mrs P "made up quizzes" for charities, including the hospital her son was cared for [66].

It is unclear why, in the case of donor families, the imputation of charitable tendencies to the deceased led to donation, and in these cases, it did not. In the following sections, other factors that overcame such attributions will be outlined: negative attitudes of the family, a lack of an obligation to carry out the deceased's wishes, and beliefs about the body.

Negative Family Attitudes

Negative attitudes, or at least uncertainty about the benefits of organ transplantation, were evident in even this limited sample. Though some respondents thought transplantation was generally a good thing, there was a lack of positive support for it. Mrs V, for example, said her husband would not have wanted to donate his organs:

Mrs V: I just felt that I couldn't let him go through with it. I didn't think that he wouldn't have wanted it that way.

GH: He wouldn't have wanted it?

MRS V: I don't think so. I think that would have been his decision [239-241].

And although most respondents asked, suggested they would accept a transplant, Mrs Q's estranged husband would not:

Miss Q: Oh yes, I mean he has really strong views. I mean to the extent he wouldn't receive one.

Mrs Q: Yeah really strongly held. And he would just have been very, very upset, so it was not, I was going to say not worth it, but I really didn't feel at anytime to add to a situation like that [373 – 380].

Yet, when I asked Mrs Q whether she would have donated if her estranged husband had not objected, she replied:

Mrs Q: If you are going to ask me if I hadn't had to take his [ex-husband's] views what it might have been, they I really, at this point in time, I don't really know. I'd like to think the answer is yes, cos I would like to think I would help another family. Em, on the other hand I'm not a hundred per cent sure [383-390].

When compared with the donor families, who demonstrated a high level of donor card ownership, neither respondents nor the deceased in this sample, had a donor card. It was also apparent that there had been no previous discussion with the deceased about their wishes regarding the matter. So, unlike the donor relatives, there was no obligation to carry out the deceased's wishes, which was found to be a key factor in overcoming their initial refusals. The deceased's donor card, therefore, is identified as a crucial element in

making the decision to donate. Its absence allows more scope for the families' negative views. Their own fears about the procedures involved in organ transplantation are more likely to enter the decision.

SOURCE OF NEGATIVE VIEWS

Fears about Mutilation

Like the donor families, negative views about organ transplantation were related to the body, and concerns about the potential compromise of its identity and integrity.¹⁰⁶ I argued earlier, that this fear stems from an embodied view of personhood at the moment of death. The body, still identifiable as the person, can lead to anxiety about the organ removal procedures. This was precisely the case for Mrs P's daughters, "cos they saw their brother lying with not a mark on him. And they couldn't figure out why they were going to cut him. That was their reaction to it, and that was why they were so upset about it" [370 - 383]. This recalls previous arguments about the status of the dead body and emphasises the continuing attachment and relationship to the deceased.

Transplantation as "Unnatural"

Yet, integrated embodiment was not the only discernible feature relating to negative attitudes about organ transplantation. Other respondents were not concerned about harm done to the identity of the deceased, but the perceived "unnaturalness" of removing one organ and integrating it into another:

Mrs Q: He [husband] em, he really honestly thinks that if your liver, or your something gives up then that is it. That's the way it's meant to be. We were never meant to get other people's liver or hearts. So anything like that, you were just meant to be and that's it. It's over, it's finished and you don't drag out, so that's his views and he's always had them [Mrs Q: 373 - 389].

For Mrs Q's estranged husband organ transplantation is against the natural order of life and compromises bodily boundaries. The source of his view is unclear, though it did not appear to have any basis in his religious values. Parallels between Mrs Q's ex-husband can be drawn with Mr X, the estranged husband in the donor sample. Both had a justifiable input when considering organ donation, and were considered legitimate decision-makers by other family members.

¹⁰⁶ As with the donor families the decision to donate or not appeared unrelated to the chosen means of disposal either through burial or cremation.

Unsure about the Utility of the Body

Mrs V's reason for refusing to donate was related to views about her husband's body. However, she was more concerned about whether his organs would be of any use:

So I just decided, and quite honestly I felt so much of him was, well I wondered if it was any use. His kidneys would be in a bad condition, his bowels were in a bad condition, his heart wasn't working, so what was the point? [Mrs V: 236-263].

So, for both donor and non-donor families, negative views are based on beliefs about the dead body. To Mrs Q's ex-husband, organ transplantation was against the "natural" order of bodily integrity; for Mrs P's daughters, it meant a procedure that would potentially mutilate their brother's body; and finally, Mrs V felt that her husband's body and its parts were too old. Though more research is required to assess this argument, fundamentally the source of family tension (for both donor and non-donor family members) regarding organ transplantation can be located to the body. Furthermore, the influence of significant others such as estranged partners and children, were pivotal in the refusal of an organ donation request. In two cases, it was a contributory factor towards refusal (Mrs P and Mrs V) and in others, such attitudes were causal (Mrs and Miss Q). It is reasonable to assume the beliefs of significant others are likely to have considerable effects, especially when their views were known to be strongly held, "you'd have to know her [daughter]. She has very strong views about everything. She is that type of person. / If I had decided yes, I think I could have persuaded her sister, but with her, never" [Mrs P: 380].

Post Mortem

The fear of bodily mutilation seemed especially pronounced in this sample, and was strongly related to other surgical procedures conducted on the body, such as post-mortems. Both the mothers interviewed said they would have objected to a post-mortem being carried out. Mrs Q initiated legal proceedings to try and halt one being conducted on her daughter. Events became more stressful when asked to identify her daughter's body in the morgue:

Mrs Q: But first of all I can remember the feeling of sheer rage, of the fact that they thought I was to look at her through a window. But by that time of course, this 'autopsy business is not something I approve of whatsoever,' and I had went on about 'butchering my daughter' [...] I still actually feel very angry about it. Treating me like a stranger to stand a distance from her. Anyway I did get to her but I was not happy, and it was a fight [390-418].

From Mrs and Miss Q's accounts, feelings of protection towards the deceased were especially pronounced. A desire to have the deceased physically close led to her coffin being kept in the house. The rationale was that "we didn't want her to be alone" [Miss Q: 609-612].

Alder Hey and Bristol

Like the donor families, the non-donor respondents were also asked about their views on events at Alder Hey. All respondents were sympathetic towards the families involved. Mrs V suggested she "certainly would have hated for a baby of mine to have been used in that way" [332]. For one respondent, the incident had a particular resonance, as she was concerned her daughter's organs might have been taken and stored without her permission:

Mrs Q: If they've actually retained any of her organs em, I'm afraid I would do it a bit more than just complain. Because they did not have that right and as far as I was then concerned they did not have the right to be violating her anyway, so against my wishes. You know, if I find that they have any part of my child is in there they will go to court if it has to. Just because they have no right. No right to keep any part of anybody [445 – 449].

For Mrs Q the emphasis is on a perceived violation of her daughter's body, and the question of "rights." That is, the body and its parts do not belong to the health professionals. In the family's view, the deceased's body belongs to them and it is their "right" to decide what happens to it.

So, even in this limited sample, negative views of organ transplantation were apparent and were related to views about the status of the body. These beliefs were not overcome and were allowed to enter the decision, because the deceased had not carried a donor card or made their wishes known. If the deceased had not stated what they wanted done with their body then, according to the family, it is their "right" to make the decision.

FACTORS THAT WOULD HAVE LED TO AGREEMENT

Regret and Social Support

In line with the findings of other studies (Tymstra *et al.* 1992, Burroughs *et al.* 1998) none of these families stated any regrets regarding their decision not to donate organs. Neither did they appear to suffer from any social stigma for choosing not to. None said they had received any negative reactions. In contrast, they related how reactions tended to take the form of having "made the right decision." "It was whatever the family

wanted. It was our decision and really not anyone else's" [Mrs Q: 497-502]. Or, "she thinks I made the right decision at that time" [Mrs P: 366-369] and "they thought I had made the right decision and that was that" [Mrs V: 285]. This suggests that others legitimated the family's decision though it is unclear why. It might be simply that others did not want to challenge the refusal. Alternatively, there might also exist a shared understanding about what the procedures involved in transplantation do to a dead body. More research is required with non-donor families in order to verify whether this is actually the case.

Stability of the Decision

The non-donor families stated no regrets about donation, and their decision appeared to be supported by others, though the actual stability of the decision was tenuous. When asked if they would make the same decision again, only Mrs V appeared undecided, claiming had it been another member of the family, she would give donation more thought.

Coupling BSD and Organ Donation

Others, however, clearly identified factors that would have contributed to agreement. Mrs P suggested, had organ donation been mentioned earlier, she would have donated. "If they had gradually told me about this the nine days I was there it might have been different. But to come and tell me that" [Mrs P: 276-277]. Mentioning organ donation prior to, or after confirmation of death, is not controversial. However, making a request for organs at the same time brain stem death is pronounced may raise suspicions that the individual was only pronounced dead because they were a potential organ donor.

Presence of a Donor Card

Despite Mrs P's suggestion that organ donation should have been mentioned earlier, this was not the only reason for non-donation. Both her daughters had negative views about organ transplantation, and her son did not carry a donor card. The stability of Mrs Q's decision was related to whether her daughter had carried a donor card:

Mrs Q: But on the other hand, if Jennifer's wishes had been known and had been definite that she had carried a donor card and that, her wishes would have been carried out.

GH: So if you had known for definite, that would have over-ridden your ex-husband?

Mrs Q: Yes cos that would have been Jennifer's wish. That's where the dividing line cuts in [385-387].

This reiterates previous arguments regarding the obligatory nature of the donor card, and how knowledge of the deceased's wishes over-rules the family's own views of organ transplantation.

Attitudes towards Financial Incentives/Presumed Consent

As with the donor families, the non-donor relatives were also asked their views on other systems, such as the introduction of financial incentives or presumed consent. Their opinions were considered important, as they have unique experiences of an organ donation request. Also their answers were thought to give some indication of support for the present system, based on voluntary, anonymous and unreciprocated gifting. Particular to non-donor relatives, however, was whether their refusal could have been changed. For example, if financial incentives were offered would they have agreed to donate? Similar to the responses from donor families, all non-donor respondents were against the introduction of financial incentives:

Miss Q: I don't think people agree to or deny organ donation, it's not money, it's *how you feel about the person* or, and I don't think money is going to change that at all.

Mrs Q: I don't think money is an issue, I think it's people's preconceived notions about someone else having your eyes, or someone else having your heart, or brain as one day they will be able to transplant [486-487, emphasis added].

This comment reiterates the importance of cultural beliefs about the body and its parts, identifying such views as the main stumbling block to donation. It is unlikely, therefore, that financial reimbursement would change such deeply-held beliefs about the nature of personhood.

Interestingly, when the issue of presumed consent was raised, one respondent said she was in favour of such a system, because it removes the family's role in the donation decision:

Mrs P: But I think it shouldn't be left to the next-of-kin. It shouldn't be. It should be if that person had a card. You don't have to ask the next-of-kin if they had the card then fair enough. If my son had a card it then wouldn't have mattered if I had said no [414-417].

Yet another respondent rejected presumed consent, but for the same reason, suggesting the donor card should over-rule the influence of the family:

I mean I know that the family can still then refuse consent, and I think that should be withdrawn. I think if you carry a donor card yourself, then that has obviously been your wishes, then I think that should be carried out, and I really don't think that a mother, a father, a husband have the right to object cos that is your choice [Mrs Q: 451–469].

So, some degree of discomfort is discernible regarding the family's role in having to consider an organ donation request. Both these quotes suggest the decision should not rest with the family, instead it should be the individual's choice.¹⁰⁷ Therefore, these families stated positive support for the present donation system, to the extent that it was claimed the role of the donor card should be strengthened, enabling their own impact on the decision to be over-ridden. Though ironically, neither of these families or their relatives had carried a donor card, and arguably donation would still not have occurred.

CONTINUING SOCIAL EXISTENCE

At the end of the interviews, the discussion turned to how respondents were coping with their bereavement. As with the donor families, it became apparent social bonds continued with the deceased, and that their relative was not excluded from the life of the living:

Mrs Q: So in the sense then, if you like, we have never allowed her to die.

GH: Yeah.

Mrs Q: We've just never allowed it to happen. She's not, not mentioned. She's here. She's with us [702-709].

And the deceased continued to be "close" to the bereaved:

Mrs P: For a long time, I kept thinking, I'm in this same house and I should have him near me. He must be about; I never get that feeling that he's with me.

GH: No?

Mrs P: But I do get the feeling that they [husband and son] are close to me. Not that they are with me [481 – 488].

The deceased's opinions were considered when decisions had to be made:

Mrs Q: We don't talk about her as not here, but talk about her. Not in the past, but not in the present either. I don't know. I can't really describe it. We just, we talk about her as if she was, well, when we would say something like 'do you remember when Jennifer said,' or Jennifer's opinion might come in. So I think, almost, with decisions, Jennifer's opinion would still count [694-699].

¹⁰⁷ Mrs V also rejected presumed consent because she felt it was a decision that should be left up to the individual [Mrs V: 337-339].

Mrs V: I've always felt that my father was there to guide me and I feel that with my husband too, you know?

GH: Is that quite comforting then?

Mrs V: Yes it is. Uh-ah.

GH: It's not depressing?

Mrs V: No, no, no [390-394].

Once more, the findings suggest relationships with the deceased do not just simply come to an end. They continue to be thought of, talked to, and the bereaved can almost feel their presence. When decisions had to be made by the bereaved, they framed it in terms of what the deceased might have done. As one respondent suggested "as long as somebody remembers, you are never actually gone. Are you?" [Mrs Q: 699].

SUMMARY

Initially, it would seem there were no significant differences between donor and non-donor families' experiences within the hospital environment and in interactions with health professionals. For example, both groups reported tensions in relationships with health professionals at local hospitals. Both groups of relatives were likely to take an active role in searching for a prognosis, turning to the body and the intensive care equipment to do so. Both donor and non-donor relatives had issues with their relative's appearance on the ventilator, whilst simultaneously acknowledging they did not have any concerns about brain stem death. In light of information communicated by health professionals, however, the donor families appeared to have a greater propensity to pronounce "social death," whereas the non-donor relatives stressed both a desire to be physically close to their next-of-kin, and to be optimistic about recovery.

The findings appear to give additional weight to the argument proposed earlier, that both donor and non-donor relatives have similar concerns regarding the integrity and identity of the deceased's body. The same concerns regarding mutilation of the body were also articulated in relation to the organ transplantation and post-mortem procedures. Indeed, negative views regarding organ transplantation stemmed from cultural beliefs about the status of the dead body and its parts. This was not entirely based on notions of embodied personhood, however. Concerns were also articulated by the non-donor family respondents about the status of the body parts, the "unnaturalness" of removing and integrating organs, and the perceived utility left in the body. Views about the body, therefore, formed the basis of refusal in both donor and non-donor families, and I would argue, negate any influence health professionals might have. This is despite one

respondent's suggestion that, should organ donation have been mentioned earlier, she would have donated.

It seems clear then, that it is the families' own beliefs that are crucial, and in the absence of a donor card, concerns are easily voiced, and take predominance. It is significant that in the non-donor family sample, neither the deceased nor the respondent carried a donor card. So there was no obligation to donate, which was a factor identifiable in overcoming initial refusals in the donor family sample. Though more evidence is desired, it would appear there is some basis to the argument discussed in Chapter 5, that inherent to organ donation and transplantation, is a paradox between the sanctity of the body and the morality of giving. The concluding chapter will turn to the implications of these findings, and will be split into two sections, dealing with policy and sociological discussion separately.

This conclusion will outline the sociological implications of the findings and also what repercussions the research has for current policy about organ donation. Though these two areas are dealt with separately, I recognise that such a division is necessarily an artificial one. Policy originates and is constructed on how best to deal with societal issues and concerns. In this sense, the relationship between policy and sociology is not conflictual or dialectical, but dialogical.

I have argued that there is a paradox intrinsic to organ donation and transplantation. The morality of gifting can work in tandem with the sanctity of the dead body. Organ donation takes place within the sphere of the moral economy, where actions are undertaken, not for profit or reward, but for the sake of others. However, tensions arise when gifting involves procedures perceived to transgress cultural beliefs about bodily identity and integrity. Indeed, the gift being given does not have a neutral cultural value, but is invested with a high level of social and emotional capital. It is not purely a “corpse” – a dead body belongs to the family and belonged to a person. In this study, nearly two thirds of donor families articulated concerns about disrespect to the deceased’s body, with four donor relatives initially refusing due to such fears, and this anxiety was noticeable in the non-donor sample. Such beliefs have a historical basis and, as was discussed in Chapter 5, public reactions to the 1832 Anatomy Act highlight how dissection provoked riots, because it was perceived as a display of disrespect towards the dead (Richardson 1988: 28). This fear of mutilation persists and, I would argue, beliefs about respect for the body are perpetuated by the deceased still being recognisable as the living person. Then, the dead body continues to be the site of personhood. What happens to the body, therefore, will remain a matter of concern to the bereaved. In part, this explains why donation was refused and why it would be refused in the future.

The Living Body and the Person

Arguably, what is done to a newly dead body should not cause concern to the bereaved; after all, it is to be disposed of. Yet views regarding interference with the deceased’s body are neither random nor spontaneous, but are mediated through an inherited cultural belief system, which emphasises care and respect. Such attitudes focusing on the body’s integrity stem from the way in which the body and the self are inter-linked in the modern era. Bodily appearance and demeanour are important elements in social interaction. Construction of the self often stems from manipulation and transformation of the living

body through practices such as cosmetic surgery, exercise regimes, dieting and fashion. The living body is perceived as an outward manifestation of a person occupying space in the physical and social world. In a society that places such high value on bodily appearance, the organs of perception are considered significant. In this research, I argued that the eyes not only give *sight*, but also offer *in-sight* into the person. The eyes have entered everyday discourse as the “windows of the soul,” a definitive expression of personal identity. The heart may remain an inner symbol of personal identity but, from the accounts presented here, it was removal of the eyes that caused relatives the most anxiety.

If an integrated system of personal and bodily identity helps us to understand respect for the body and organ restriction, a belief the body does not hold a relationship to personal identity explains why they were not. Although the medical donor family respondents had the same ties to the deceased, they were more likely to stress the dead body was not the person. It is unclear why this was the case. One can assume it is related to the cultivation of clinical detachment based on Cartesian Dualism, and an awareness of the benefits modern medicine can bring about. As stated earlier, such differences in attitude and belief between medical and non-medical respondents were not clear cut, however. In a few cases, those with medical backgrounds also restricted organs and had concerns about mutilation.

The Dead Person and the Dead Body.

I have argued concerns regarding the body’s integrity are caused by equating the dead body with the once living person. In life, the living person and their body are inextricably linked. There is no reason, therefore, to believe separation occurs immediately on the occasion of a person’s death. In organ donation, for example, the findings suggest that feelings of attachment are not simply switched off with the ventilator. For the majority of donor and non-donor families, the dead body continues to be imbued with the same emotional significance because it continues to represent the person that once was.

Death, does not denote the end of the relationship to that person, whether a child or parent; relationships do not just simply cease to be. Though the next-of-kin in this sample realised and accepted the person to be corporeally dead, to the extent they may even pronounce death themselves, the relational and personal elements persist. In other words, dead people do not socially die. The bereaved’s relationship with the deceased continues and was found to be a significant cause of difficulties concerning donation. As

shown, most of the mothers of young donors, articulated concerns regarding death and bodily integrity. For them, their maternal role continued and they wanted to protect their child not only in life, but also from events that happen to them after death. This also helps to understand why parents became so distressed post-Alder Hey, when their children's organs were kept without permission.

Yet if organ donation is to occur, values that equate the person with their dead body must cease at some point; their organs are to be removed. Beliefs of continuing corporeal existence post-death are antithetical to donation. In countries such as Japan, organ donation is not widely practised and this is, in part, due to cultural and religious constructions of the deceased's need for their body in the early days of the after-life. In comparison, accounts offered by donor family respondents assumed that the body is not needed in the after-life, or they believed no such phenomenon exists. So, this explains why donor families stated that "when you're dead, you're dead."

The Filtering of Cultural Beliefs – Health Professionals

Wider beliefs about the status of the dead body can cause anxiety when procedures, such as organ transplantation, are thought to harm and show disrespect to the person's body. Though the health professionals may have recognised the relatives' feelings of attachment, some families articulated concern regarding their role in negotiating an organ donation request. Some donor and non-donor families suggested they were not offered enough support about the procedures involved, or that health professionals did not allow them to be physically close to their next-of-kin. Such concern may have been caused by health professionals having to negotiate their "double burden" of caring for the patient and caring for the family.

The way in which health professionals communicate with the family, both by direct and tacit communication, can help relatives anticipate the inevitability of death. Whether or not using tacit communication is a conscious strategy that health professionals employ, remains unclear. What is apparent is that within an intensive care unit environment, relatives of patients are not passive information receivers, but active agents seeking an indication of the prognosis. So, health professional communication is crucial in this aspect, but it is not the deciding factor when relatives are considering an organ donation

request. This is because the families' own beliefs and attitudes can either contradict or reinforce the messages health professionals provide.¹⁰⁸

The Family

Carrying a donor card is a decision an individual may make during their lifetime. After death, however, this decision to donate is mediated through family dynamics. In other words, the family can be considered "proxy donors." In this study, the decision to donate was informed by normative rules regarding who the legitimate decision-maker was. This perception was based, primarily on marital ties, and then on blood ties to the deceased. The strength of marital ties means, in some cases, the family of origin can consider an ex-husband the main decision-maker and/or have a significant input into the decision. Consultations with children were not just symbolic gestures, but were shown to have an important influence. Uncertainty about the decision to donate stemmed from two sources, previous family conflict and values about the integrity of the body. In the absence of a donor card the families' own beliefs entered the decision. According to donor and non-donor relatives' accounts, it is their right to decide what happens to the deceased's body, due to their previous relationship with them. In the absence of a donor card or knowledge of the deceased's wishes, there is scope for the relatives' positive and negative attitudes to be realised. For example, in all cases of refusal, the wishes of the deceased were unknown and the relatives did not carry donor cards. In contrast, all donor families donated in the presence of a donor card, and were likely to carry a card themselves. Donor families stated they had an obligation to donate, because of their previous social relationship with the deceased. It seems the continuing relationship to the deceased, therefore, engenders on-going obligations.

Obligation, Self-interest and Reciprocation – A Return to the Maussian Paradigm?

Then, because it is a duty to carry out the deceased's wishes this overcomes negative views about the value of organ donation. Quite simply, an obligation to give over-rules the families' fear of mutilation. Distinct elements of Mauss's obligations to give, to receive and to reciprocate were discovered in the donor family accounts. They said they donated because there was an obligation to give. There was also an obligation for the recipient to receive the gift and make it a success. If the gift was unsuccessful this could result in dissonance for the donor family. Additionally, donor families seemed to gain an extra emotional reward if the organ went to a child because they imagined the gift would

¹⁰⁸ Although it appears a significant lack of health professional information and support seems more likely to lead to regret on behalf of the families. Mrs G, for example, who had donated because of her husband's donor card would not donate again due to her distressing experience in the local hospital.

be more beneficial. The donor families also recognised that the recipient may feel an obligation to reciprocate, though this was stated as unwanted. There was a reward from donation, as donor families said they received an emotional benefit from knowing some good had come out of death. However, they suggested this was not an expected outcome and was not comparable to the loss they had suffered. It is debatable to what extent this can be defined as reciprocation, at least in the strictly Maussian use of the word. Reciprocation did not come from the recipient; it was mostly unexpected, and was not equal to the gift given.

Voluntary, Other Motivated, Unreciprocated Gifting – Altruism in Action?

In the absence of a donor card and a lack of obligation to give, the donor families empathised with another's need. Donor families suggested that this need was known, though the recipients themselves were not. Due to the distance in social bonds, "unknown others" were imagined and empathised with. This shared social construct of the "unknown other," however, had concrete forms. The donor families imagined them to be a child or a husband, they had a job and/or a family, they lived in Glasgow, London or Bristol. Relatives donated because as social actors they imagined, empathised, and sympathised with others' needs and there was an expectation that these others could, and would do the same. Like Titmuss's (1970) blood donors, the donor families asked themselves: what if they were the ones in need?

We are, by definition, social beings living in society and this necessarily implies at the basic level, a degree of co-operation and empathy. Donation highlights that, though we live in a society constituted by strangers, they are known to us. Fundamentally, they are the same as us through a shared human condition. As individuals, we are very much aware of having a position within a social network that necessarily links us to others within society. Through donation the relatives had in a sense, reaffirmed their social bonds. As Elias had argued, the "figuration" of people demonstrates, though we may not feel interdependent or tied to others, such subtle bonds are powerful forces (quoted in Burkitt 1994: 19). In comparison to Titmuss's claim, therefore, that blood donation *strengthens* social bonds, the argument advanced here is more modest: donation is an *expression* of these social bonds. Such actions take place within a moral economy and signify the interconnected nature of our relationships to one another.

From this, one might conclude the organ donation system is premised on the sociability of individuals. Individuals who participate in such a system know that it is constructed on

voluntary, anonymous and unreciprocated gifting. Their participation, therefore, might be defined as altruistic. But, as the findings demonstrate, altruism does not explain why all the donor families donated, only that they participated in a system based on elements associated with altruism.

Comparing Donor and Non-Donor Families

So, altruism as an explanation for donating behaviour is limited. It does not lead any further in understanding the nuanced and subtle reasons offered by donor relatives, as to why they decided to donate their relative's organs. Nor does it acknowledge that the majority of the donor families were under a perceived obligation to do so. It also creates a picture of misanthropic non-donor relatives, who are uncaring and unfeeling about the need of others. This was not the case, non-donor relatives were just as likely to donate blood and be involved in previous charitable activities. Indeed, non-donor families shared similar experiences with donor families. As with donor families, they experienced concerns about the deceased being maintained on the ventilator. Both groups also complained about a lack of health professional support. Equally, donor and non-donor families were anxious about what the organ transplantation procedures involved. Both groups stated no regrets about the decisions they had taken. But unlike the donor families, non-donor relatives either knew that the deceased did not want to donate, or were unsure about what they would have wanted. This uncertainty was exacerbated by negative beliefs about the value of organ donation. None of the non-donor respondents carried donor cards, and there was mention of an individual unwilling to accept an organ transplant. So from the non-donor family interviews, it appears that their experiences did not differ substantially from the donor families, although their attitudes and belief systems about the value of organ donation did.

Policy Change – Presumed Consent and Financial Incentives

This research offers interesting comparisons between donor and non-donor family experiences, attitudes, and belief systems, highlighting similarities and differences. But what policy implications can be drawn? What recommendations for increasing the present supply of organs can be made based on the evidence presented in this thesis? The unanimous rejection by all respondents of the economists' "financial incentive" solution to improving the organ donation system, demonstrates money is simply not the answer, nor as economists suggest, the main motivator. Recall one non-donor respondent's response, "I don't think people agree to or deny organ donation, it's not money, it's *how you feel about the person* or, and I don't think money is going to change that at all [Miss

Q: 486-487, emphasis added]. Organs are not to be equated with commodities that are exchanged within a market arena, nor does donating follow the principles of the political economy. Reactions to presumed consent were mixed, however. Those who rejected presumed consent outright tended to emphasise the importance of giving, and the individual's right to make the decision on what organs to donate. For example, all those who restricted organs were against presumed consent, and those who did not restrict organs, were in favour. For those who restricted organs, they were imbued with a high degree of symbolic and emotional value and taking them, therefore, was not acceptable. Respondents who were in favour of presumed consent legislation emphasised a "soft version," which maintained the relatives' right to refuse.

The British Medical Association has recommended a soft version of presumed consent legislation should be introduced, though as outlined in Chapter 2 the government currently rejects such a proposal, remaining unconvinced this is the answer. Indeed, as argued earlier, a soft version of presumed consent would not diminish the relatives' refusal rate. It is clear that changing the present system to one of a "soft" version of presumed consent, seems only a change of emphasis, rather than procedure. In other words, the relatives are still able to veto the decision. Further, the wider social repercussions of introducing either version of presumed consent legislation, need to be carefully considered. Public acceptance and confidence are key to understanding how the present procurement system works. Crucially, organ donation and transplantation reflect the norms and values of any given society. The present UK organ procurement system reflects a wider, liberal ideology that emphasises individual rights, specifically, the right to agree or refuse organ donation. Additionally, given the current outcry over the "retention of organs" scandal in several NHS trusts throughout the UK, it is unlikely legislation regarding presumed consent will be introduced in the foreseeable future. The Donaldson Report (2001) suggested legislation regarding autopsies and the retention of organs requires alteration, so that the express permission from relatives is sought. It seems probable that the 1961 Human Tissue Act, on which organ transplantation is based, will be modified so that health professionals will have to seek positive agreement for both transplantation and post-mortems, rather than "ascertaining lack of objection."¹⁰⁹

¹⁰⁹ The Review Group into the Retention of Organs, chaired by Professor McLean has submitted its final report to the Scottish Executive (November 2001) recommending that the 1961 Human Tissue Act is repealed. Whether or not the Scottish Executive decide to take this forward remains to be seen.

Organisational Change – Improvements at the Local Level

Rather than examining public attitudes to other systems, whose efficacy and applicability are doubtful, and are already rejected by the UK government, the promotion of the current system is the only viable, short-term option. In light of the preceding discussion, several recommendations can be made regarding both the source of organs, and the way they are procured. Clearly, in this sample, tensions with health professionals were more likely to occur at local hospitals. As such, some of the organisation level aspects of the Spanish model discussed in Chapter 2 may be worth further examination, and its applicability to Scotland assessed. This would lead to a promotion of organ transplantation in *all* hospitals. Given the need for clear information and support at an early stage, mentioned as a key issue in both donor and non-donor family accounts, then health professionals based in local hospitals with training and experience in organ donation may have some form of positive impact. Yet the implementation of the Spanish system would require further resources, an unlikely outcome given the present state of funding within the NHS. Moreover, the stress the Spanish model places on donor identification as opposed to referral, and the persistent way the request is made, could have negative repercussions. Not enough is known of the experiences of Spanish families who have been approached with an organ donation request. Finally, whether or not this would increase the donation rate is unclear, though it would certainly reduce some relatives' anxiety and distress post-donation. Both donor and non-donor family respondents suggested several strategies health professionals could employ to meet their needs, during the intensely emotional and difficult time of having a relative in intensive care:

- Respondents said health professionals need to provide information and support about the potential donor at the earliest opportunity, with some indication if possible of potential for recovery or otherwise. Clear communication has several important functions; first it can help overcome relatives' alienation from the environment through the establishment of ease and trust. Second, the relatives are in a position to assess for themselves the likelihood for recovery. Third, it can aid an understanding of brain stem death. Post-donation, continuing information and support allows an opportunity for them to ask questions, and makes the donation seem more sincere.
- With information, relatives will, in most cases, make some form of judgement regarding their relative's condition. In other words, by implicitly being prepared for the worst, they can exert some form of control by making their own conclusions based on available information. If they have been prepared for the inevitable, they

will pronounce social death, prior to the establishment of death by medical criteria. Relatives are not passive participants in the medical system, but are active agents making their own diagnosis.

- In general, no significant difficulties were articulated by non-donor and donor relatives regarding the ventilator, brain stem death tests, and the diagnosis of brain stem death, suggesting that neither relatives nor health professionals in this sample suffered from the same confusion and dissonance found in other studies. Only in a minority of cases were doubts and concerns expressed. However, the repercussions of this caused high levels of distress and anxiety for the respondents. Again, avoiding jargon and words such as “harvesting,” and employing concepts familiar to the relatives, can help them understand and begin to deal with the situation.
- Depending on circumstances, relatives said they needed to be given some amount of time *after* brain stem death, before an official request for organs is made. Though there appeared no harm in mentioning the topic prior to this (and one non-donor family member, Mrs P, said this would turn a refusal into agreement), making an actual request risks coupling together brain stem death and organ transplantation. This may exacerbate existing doubts regarding the health professionals’ motivation and diagnosis of the donor. Those respondents who were given reasonable amounts of time between their relative being admitted, the pronouncement of brain stem death, and an organ request, were the least likely to express concerns about the process.
- Treating the donor’s body with respect is crucial to facilitating the organ donation process. Viewing it as merely a source for organs creates tension. To the family, the body still represents the person, and remains the focal point where they can express their emotions. This is particularly true for parents of young donors, highlighting the strength of the continuing parental role, to protect and care for one’s child.
- Violation of the body’s integrity caused dissonance for some relatives, who required further reassurances regarding the procedures involved in removing the organs. Some donor relatives developed coping strategies in order to deal with the tension caused by donation and transplantation.
- The request for organs should be made in a private place in the hospital, preferably with only significant members of the family present. A lack of uniform, and removal of theatre gowns, can help the families feel more at ease. Requesting organ donation in a wider familial environment can exacerbate previous familial tension and in the absence of a donor card, allow leeway for the families’ beliefs to enter the decision.

Improving the Present System: The Role of the Donor Card

In this sample, the presence of a donor card and knowledge of the deceased's wishes appeared to be the main determining factor causing donation to occur. The obligation to give overcame the relatives' concerns about what the organ removal procedures might involve. The presence of a donor card and/or knowledge of the deceased's wishes was a pivotal factor in overcoming refusal, both in the donor and non-donor family samples. For example, at least one non-donor respondent said she would not have refused if her daughter had a donor card.

Then, the key role of the donor card is not only about expressing an individual's wishes regarding donation, but is also crucial in overcoming the families' negative beliefs or concerns. Support for the present donation system was high in both groups, with respondents offering suggestions for improvements, rather than changes to the procurement system. Some thought donor cards could be made more visible and accessible. Public campaigns, similar to the recent drinking and driving advertisements were suggested as being useful, as was education about organ donation in secondary schools. The general agreement was that the role of the donor card should be more widely promoted and positive belief systems about the value of organ donation should be encouraged.

Alternative Systems – Living Donation

Recognition, however, also needs to be given to the fact that there are limits on what any country can hope to achieve in increasing the cadaveric donation rate. As outlined in Chapter 2, the cadaveric donor pool is steadily decreasing, in part, due to better road safety, but also due to improved medical technologies that can identify individuals who will not survive and, therefore, not taken to intensive care. Other countries, such as Norway, have overcome this problem by increasing their rates of living donation. Living donors can donate any of their paired organs or regenerative ones, such as the liver. Living donation seems to be gaining popularity in this country, and such a trend is likely to continue. Increasing utilisation of living donors, related or otherwise, may have a significant impact on donation rates, and its employment is not limited by powerful cultural beliefs about death and the dead body. This is despite concerns of some medical professionals, ethicists and researchers, regarding the potential risks to the donor involved, and the impact on family dynamics. It would be desirable for more research to be carried out in this area given the paucity of information available. For example, what would be the costs and the benefits to the living donor and recipient? Is there a certain

amount of emotional pressure, perhaps even blackmail involved, within the family? What happens to the relationship after a successful donation, and what is the effect of rejection on family dynamics?

The findings from this research suggest two main strategies that can increase the present supply of organs; improvements to the present voluntary, opting-in system, and an examination of alternative sources, such as living donation. These recommendations for policy target specific areas of weakness in the present system. They are based on research with individuals who have participated within it, and they do not risk damaging public confidence in the way that cadaveric organs are procured. Therefore, in ending, it is fitting that we return to the statement made at the beginning of this thesis, and recognise negotiating the paradox of organ donation and transplantation will remain a precarious task.

APPENDIX A - INTERVIEW SCHEDULE

Answers will be treated in the strictest confidence and your identity will remain anonymous. Would you mind if I tape your answers? Some of these questions are quite sensitive so please let me know whether you feel you are unable to answer them. This might be difficult for you but please don't worry if you get upset. Just tell whether or not you want me to stop the interview. Would you like to ask me anything before we begin?

Can I just ask you how you felt when you received the letter?

A. DEMOGRAPHICS OF RESPONDENT

1. First of all do you mind just telling me a little bit about yourself?
2. How old are you?
3. Are you married?
4. Have you lived here all your life?
 - **No**- where did you live previous?
5. Are you currently employed?
 - **Yes**- what do you do? Did you require qualifications?
 - **No**- have you previously been employed?
 - **Yes**- what did you do? Did you require qualifications?
6. Do you have any hobbies?
7. Do you donate money to or get involved with any charity or voluntary work?
8. Do you belong to a religion?
 - **Yes**– what religion are you?
 - Do you attend Church
 - Roughly how often do you attend?
 - Do you attend with other members of the family?
9. Can you tell me a little bit about your immediate family?

B. ABOUT THE DECEASED

10. Could you tell me a little about the deceased? DEMOGRAPHICS

11. What was your relationship to the deceased? [

12. How long did you know them for?

13. How would you describe your relationship with them?

14. Would you describe it as a close relationship?

- *No*- why do you say that?

- *Yes* did you spend a lot of time together?

15. How would you describe them to me as a person?

16. Do you think about ... at all now?

17. *No*- were there any times that you might have thought about them?

- *Yes*- how often? Has this remained the same or has it changed?

- Is there any particular times or special occasions that might start you thinking about them?

- Are there any other times that you might think about them?

- How do you feel at these times?

18. Do you feel close to them at these times?

19. Some people have told me that if they are faced with a difficult decision to make they try and think what their loved one's opinion would have been. Does that sound like something you have done or might do?

20. Some people have told me that after bereavement they still occasionally dream and talk to their loved one. Does anything like that sound familiar to you?

21. In your own time – can you tell me the circumstances that led to their death?

C BRAIN DEATH

22. When did you begin to realise the seriousness of their condition?

23. At what time did the health professionals make you aware of the diagnosis of brain death?
24. Had you ever heard of the term brain death before?
- **Yes- where** had you heard it before?
 - What did you understand it to mean?
25. What was your initial reaction to the diagnosis of brain death?
26. When the diagnosis of brain death was made were you able to understand what the consequences were?
27. Did the health professionals take time to help you and your family understand the diagnosis?
28. Was there anything about the diagnosis that was difficult to understand?
29. Had the procedures of the brain death test been explained to you?
30. Was the request for organs made prior to a diagnosis of brain death or after?
31. Did you have to sign a consent form about the removal of life support?
32. Did you decide to stay or go home at that point?

D. DETAILS OF THE PROCUREMENT PROCESS

Did a family member or a health professional first raise the donation of organs?

- **if family member-**
 - Who was it that made the offer?
 - Why do you think the offer was made?
 - When did they decide to offer?
 - Was this an individual decision or a result of discussion with other members of the family?
- **if health professional**
 - 33. Was it a health professional that was known to the family?
 - 34. And did they ask you or another member of the family?

35. How was the request made?
36. Where was the request made?
37. Did they ask for specific organs or a more general request?
38. Can you recall what your initial reaction was to the request?
39. Can you remember how much time was given to you and your family to make the decision?
- **Yes**- did you feel that that was enough time?
40. In your opinion did you feel under any pressure to donate?
- **Yes** what was the source?
 - Did this influence your decision

E. FAMILY DYNAMICS

41. Was the decision made immediately or was some time needed to think it over?
42. Can you remember who was involved in making the decision?
43. Was there any particular reason for these people being involved?
44. Do you know if anyone felt excluded from the decision?
45. Who made the final decision?
46. Did people generally agree about the decision?
- **No** who didn't agree? Why?
47. Did you talk to others about the decision that had been made?
- **Yes** who were they?
 - What were the reactions
 - **No** Was there any particular reasons for this

F. THE BODY – DONOR FAMILIES ONLY

48. Once organ donation had been agreed what happened next?
49. And did you place any restrictions on the organs that could be transplanted?

- *Yes* what organs did you restrict?
- What led you to make these restrictions?
- *No* had you thought about making any restrictions?
- *Yes* why didn't you?

50. Were you concerned about the removal of the organs?

- *Yes- why* were you concerned?

51. If a post mortem had been required would you have had any objections?

- *Yes* why would you have objected?
- *No* do you think that there is any difference between a post mortem and organ donation?

52. Did you have a burial or a cremation?

- Did organ donation effect the decision to have a burial or cremation?

G. RECIPIENT FAMILIES/FOLLOW – UP CARE

53. Have you ever thought about the recipient or the recipient's family?

- *Yes-* did you think about them when making the decision to donate?
- Did you think about them after the decision to donate?
- Is it more about the family or the recipient or about the same?

54. Have you received any follow-up care from the transplant co-ordinator?

- *Yes* – what was? Was it sufficient?
- *No* – would you like to hear from them? Why?

55. Did you receive a letter about the recipient?

56. *Yes* how did you feel about that?

57. Do you know how many recipients received organs?

58. Have you ever been contacted by the transplant co-ordinator on the recipient's behalf?

- *Yes* - what was your initial reaction?

59. Have you tried to contact the recipient through the transplant co-ordinator?

- *No* have you ever considered it?

- *Yes* was there a reason that you didn't try to contact them?
- *Yes*- was there a reason why you wanted to contact them?
- Were you successful?
- *No*- why were you unsuccessful?
- *Yes* what was the recipient's response?
- Would you be willing to meet?
- Do you still have contact with each other?

H. BELIEFS AND PREVIOUS KNOWLEDGE ABOUT ORGAN DONATION

60. Has organ donation ever been discussed in the family?
61. Did you know how----- felt about organ donation?
- *Yes* carry a donor card/driving licence/donor register?
 - *No* how did you make the decision?
62. Did----- or anyone in your family give blood regularly.
63. Do you or any member of your family carry a donor card?
64. Do you think that people benefit from a transplant?
65. Would you be willing to accept a transplant?

I. DONATION IN RETROSPECTION

66. Looking back now was there anything specific that influenced your decision?
67. donated because
- altruism;
 - continuing bodily immortality;
 - felt in/directly obliged to; knew wishes of donor;
 - something good comes out of death,
 - that was the type of person they were
68. In retrospect how do you feel about the decision?

69. Would you donate again?

70. Do you feel you have received anything from the donation?

71. Did you hear about events at Alder Hey and Bristol hospitals?

72. There are proposals to introduce other systems because the present system is failing to meet the demand for organs. One such system is called presumed consent or opting-out where unless a person has recorded their objections the hospital is allowed to take the organs. Would you support or be against the introduction of this system?

- Reasons for answer?
- **Support** if the relatives objected should the organs still be removed?

73. There is also another system where the relatives are offered some form of compensation if they donate? Again would you be in favour or against introducing this system?

- Reasons for that?
- **Support-** what kind of compensation would be acceptable in your opinion?

74. Is there anything else that you think is important that we haven't covered

RESEARCH INFORMATION SHEET

**AN INVESTIGATION INTO FAMILIES' EXPERIENCES OF A DISCUSSION
ABOUT ORGAN DONATION IN SCOTLAND.**

You are being invited to take part in the above study. It is investigating Scottish families' experiences of a discussion about organ donation and how people reach the decisions that are right for them. Sharing these experiences may be difficult for you so please take your time to decide whether you want to take part or not. You may like to discuss it with family and friends. It is important that you understand why the study is being conducted and what your participation might involve. If you think you might be willing to take part I would be grateful if you could please take the time to read the information below.

WHO AM I?

My name is Gill Haddow and I am conducting doctorate research in the Sociology Department at Edinburgh University and have been studying organ donation and transplantation for three years. I am an independent researcher and you can be assured of my neutrality in this area.

WHAT IS THE RESEARCH ABOUT?

Little is known about families who have had experiences of an organ donation request. This research therefore is important, in its aim to help understand and improve the present voluntary system. To find out more about this, the Economic and Social Research Council has funded me to research this area. I approached Mrs Jackie Bradie and Deirdre Walsh (transplant co-ordinators), and Drs. J. Forsythe, (renal transplant surgeon), I. Grant (consultant anaesthetist) and Mike Souter (consultant in neuroanaesthesia) for their help and permission to contact you. Dr S. Mackenzie (consultant anaesthetist) has also agreed to act as an independent advisor for the duration of the study. If you would like to contact Dr Mackenzie to discuss your participation in this study, please feel free to call him on (0131) 536 1000, and ask for page number, 6431.

WHAT WOULD IT INVOLVE?

The extent of your participation would take the form of a one-off interview that will be tape-recorded and will last about an hour or two with yourself. During the interview, you can if you wish have a friend or another member of your family there with you for support as you may find the interview quite tiring and emotional.

Your experiences are unique and your views are important on a range of issues such as, having a relative in intensive care, coping with your relative being on a ventilator, the discussion of brain stem death and organ donation and the impact of bereavement for you and your family.

The decision to take part in this research is entirely voluntary and you are under no obligation whatsoever to do so. Even if you do decide to participate, you may withdraw at any time, without offering any reasons. I realise that you may feel anxious about participating so if for any reason you feel that you cannot take part, I would be grateful if you could let me know your decision by filling in Section A of the Consent Form on pg. 3., returning it in the stamped addressed envelope provided.

However, if you think that you might be interested in taking part, please read the 'Consent Form' carefully before filling in Section A, Section B and Section C and return all the completed sections to myself. Depending on your answer, I will then contact you to arrange an interview, which should last about an hour or two, at a location and time that suits you best.

PERMISSION TO CONTACT YOUR GP

Because this is a particularly sensitive area of research your GP needs to be informed of your intention to participate. This is why I have asked you for your GP's name and address in the Consent Form.

ANONYMITY AND CONFIDENTIALITY

The interview, unless you have any objections will be tape-recorded. However, **complete confidentiality and anonymity is guaranteed**. The answers and information you give me will be treated in the strictest confidence and the final report will make no reference to individual persons.

FURTHER QUESTIONS?

I appreciate that deciding whether or not to take part in this study may be difficult. Yet if you have any questions at all about taking part in this study, no matter how insignificant you think they might be, then do not hesitate to contact me at:

Gill Haddow
Sociology Department
Edinburgh University
18 Buccleuch Place
Edinburgh
EH8 9LN

Day-time telephone: (0131) 650 3988/4001

Evenings: (0131) 556 9536

E-mail: g.m.haddow@sms.ed.ac.uk

I hope I have not caused you any unnecessary distress in contacting you and please accept my sincere apologies if I have done so.

Yours Sincerely

Gill Haddow MA, MSc

CONSENT FORM

Your help is extremely valuable to this research. I am grateful to you for taking the time to consider whether you are prepared to assist me, especially as the topic may be particularly difficult and emotive for you:

- If you have decided to take part then complete all the Sections below: Section A, Section B and Section C, returning it in the stamped addressed envelope provided.
- If you have chosen not to participate, then please complete Section A only and return it in the stamped addressed envelope provided.

SECTION A:

I WILL/WILL NOT BE ABLE TO TAKE PART IN THIS RESEARCH (delete as appropriate) AND PLEASE COMPLETE:

Name-----

Address-----

Tel. No.-----

SECTION B:

PLEASE SIGN ONLY IF YOU AGREE WITH THE FOLLOWING STATEMENTS AND HAVE DECIDED TO PARTICIPATE:

 I have voluntarily agreed to take part in this study.

 I have been adequately informed about this research and have had the opportunity to ask questions.

 I understand that I can withdraw from this research at any time.

 I understand that I am not being rewarded financially or otherwise for my participation.

 I understand that my participation in this study although tape-recorded, will be anonymous and will be treated in the strictest confidence.

 I have given my permission for the researcher to contact my GP whose name and address I have provided below.

Signature:

Date:

SECTION C: PLEASE PROVIDE YOUR G.P's NAME AND ADDRESS

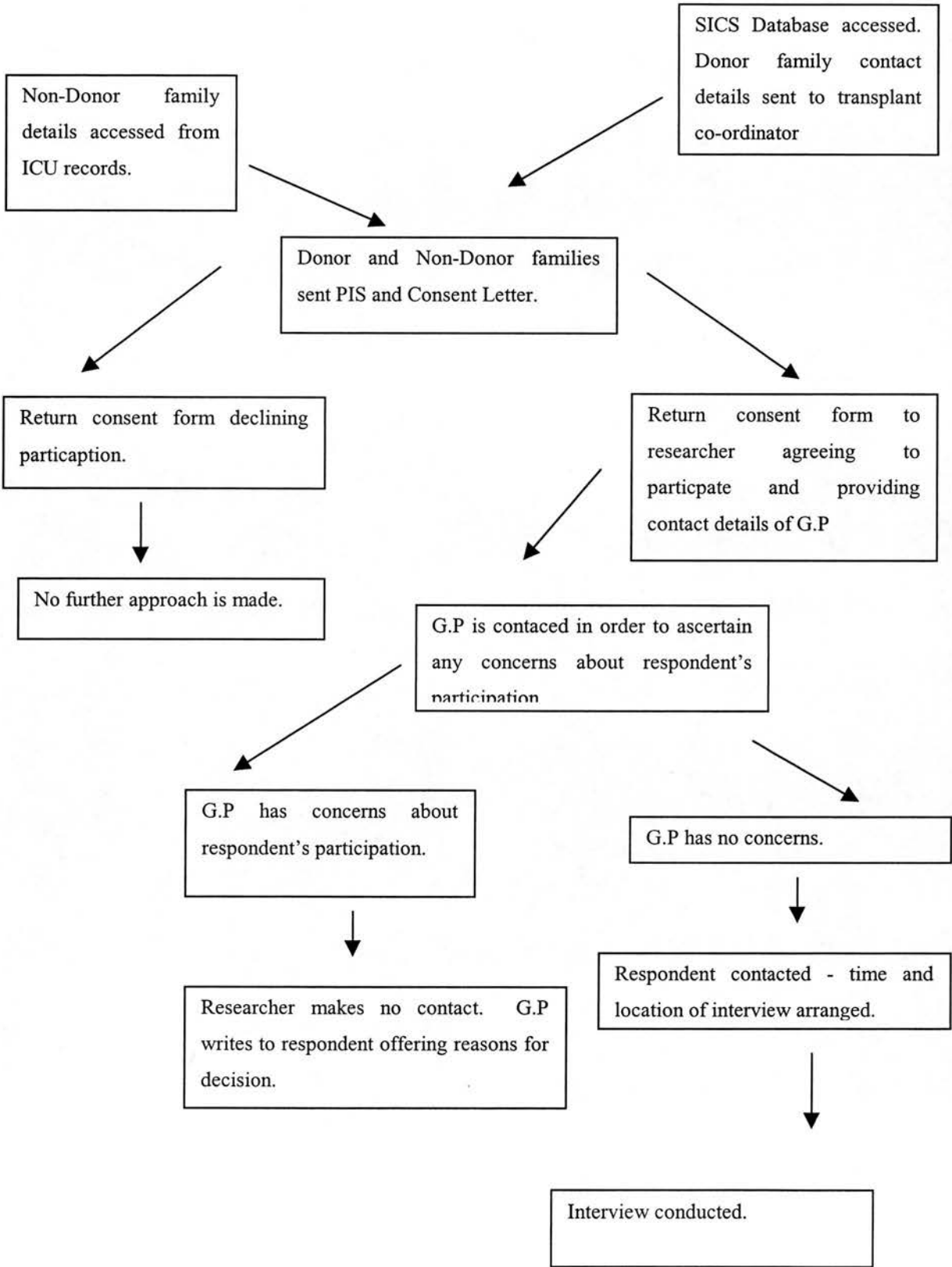
Name-----

Address-----

Tel. No.-----

Thank you for your co-operation.

APPENDIX C: FLOW-CHART OF RECRUITMENT PROCESS



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